

An investigation into the views of young people with Autism Spectrum Condition (aged 14-19) on their use of social media

Submitted by Alexander de Sausmarez to the University of Exeter as a thesis for the degree of Doctor of Educational Psychology in Educational Child and Community Psychology, May 2018

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Abstract

Introduction: Young people with Autism Spectrum Condition (ASC) have been shown to be at higher risk of many negative factors associated with internet use. However, many anecdotal reports have suggested that social media can have a positive impact on young people with ASC, with the emergence of social media for the ASC population being compared to the emergence of sign language in the deaf community. This has been hypothesised to be due to online communication lessening “*the emotional, social and time pressures experienced in offline situations*” (Benford and Standen, 2009 p.2).

Method: This research explored young people (aged 14-19) with ASCs’ digital identity and how they feel it relates to; relationships, psychological well-being and life outcomes.

Phase one data collection was through a questionnaire formed of three standardised measures to assess; digital identity (the Autism Digital Identity Scale, adapted from the Deaf Acculturation Scale; Maxwell-McCaw & Zea, 2011), relationship formation (the Friendship Scale; Baron-Cohen & Wheelwright, 2003), and well-being (the Moods and Feelings Questionnaire; Angold & Costello, 1987). Four questions on a Likert scale were used to ascertain views about life outcomes.

For phase two, participants were asked to contribute to an online forum, where a qualitative thematic analysis and a systematic qualitative analysis were undertaken to find any phenomena occurring. Two participants were chosen as case studies.

Results: A relationship was found between those who identify as non-autistic online and enjoy close relationships. A relationship is found between those with an autistic digital identity and those who feel that the internet will support their life outcomes with regards

to forming relationships. A negative correlation was found between non-autistic digital identity and believing the internet will improve both work and life outcomes.

A variety of sub-categories arose from the qualitative analysis, including; choosing/disclosing a non-autistic digital identity, advantages to online communication, removal of eye-contact/time pressures online, making new friends, online social support and confidence in online interaction.

Discussion: The findings from both phase one and phase two are discussed in relation to previous research. Potential areas of further research are discussed, while highlighting a paucity in research for training appropriate use of social media for young people with ASC.

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Abbreviations

| Abbreviation | Meaning |
|--------------|--|
| ASC | Autism Spectrum Condition |
| RQ | Research Question |
| DSM-V | Fifth edition of the Diagnostic and Statistical Manual of Mental Disorders |
| DAS | Deaf Acculturation Scale |
| ADIS | Autistic Digital Identity Scale |
| NADIS | Non-Autistic Digital Identity Scale |
| FQ | The Friendship Questionnaire |
| MFQ | The Moods and Feelings Questionnaire (short-form) |
| LOr | Life Outcomes score (relating to friendships and partners) |
| Low | Life Outcomes score (relating to work and achievement at school/college) |
| EPS | Educational Psychology Service |

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Chapter 1: Introduction

1.1 Rationale

Social media is defined by the Oxford University Press (2016) as “*websites and applications that enable users to create and share content or to participate in social networking*”. It can also be described as any website which can allow social interaction, examples of these are “*Facebook, Myspace, and Twitter; gaming sites and virtual worlds such as Club Penguin, Second Life, and the Sims; video sites such as YouTube; and blogs*” (O’Keeffe & Clarke-Pearson, 2011, p.800). Use of social media has become commonplace for many people across the world, with empirical research showing a significant number of internet users spend several hours online every day (Eynon & Malmberg, 2011; Selfhout et al., 2010). There has been a widespread debate over the ‘opportunities and risks’ associated with internet use (Livingstone, 2013). For example, some studies have highlighted risks by reporting correlations between internet use and loneliness (Kraut, Patterson, Lundmark, & Kiesler, 1998), yet some later studies have found there are variations related to the amount and nature of online activity the individual is engaging in (Kraut et al., 2002; Shillair, Rikard, Cotten, & Tsai, 2015; Skues, Williams, Oldmeadow, & Wise, 2016; Zhao, 2006). There are also variations in reasons for use of social media, and the function that it serves. There are indications that for certain populations (e.g., individuals with autism spectrum condition), internet use is extensive (Shane-Simpson, Brooks, & Obeid, 2016). It has been speculated that many young people with autism spectrum condition (ASC) are at higher risk of many of the negative factors associated with internet use, such as isolation and cyber-bullying (Müller, Schuler, & Yates, 2008; Schroeder, Cappadocia, Bebkö, Pepler, & Weiss, 2014).

In the following introduction, the extent to which young people with ASC identify with others with the same diagnostic label through online activity will be considered, as well as how this may affect their psychological well-being, ability to form meaningful relationships and views on life outcomes. I will begin by defining ASC, followed by discussing related issues such as neurodiversity, diagnosis and gender. I will then review key issues relating to digital media and outline identity formation. I will then discuss ASC, review key issues relating to the inter-relationships between ASC identity and digital identity. This will be set in the context of relationship formation for adolescents (and more specifically adolescents with ASC), psychological and emotional well-being (also more specifically for adults with ASC) and views on life outcomes for adolescents with ASC.

Due to a paucity in research relating to the specific constructs outlined, a broader literature search was undertaken from texts written by practitioners who have published research on ASC and/or social media, search engines on the internet and peer-reviewed journals. Following this exploration, I searched using terms with more specificity, such as 'autism social media', 'autism mental health' and 'autism life outcomes' on online research search engines (e.g., EBSCO- E-Journals, PsycINFO). Further research was acquired from the references within the sources found from the methods outlined above. I will begin by discussing ASC, the characteristics those with ASC may display and why I have chosen to discuss it in this way.

1.2 Literature review

1.2.1 Autism Spectrum Condition

There is a debate around definitions of autism. The definitional framework of the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-V) adopts the term autism spectrum disorder (American Psychiatric Association, 2013). However, throughout my research I will be defining autism as a condition (or autism spectrum condition; ASC), as it fits with recent advances within the field of autism (Russell & Norwich, 2012). Furthermore, a ‘disorder’ is described in the Oxford Dictionary (Oxford University Press, 2016) as: *“an illness that disrupts normal physical or mental functions”*. However, ‘condition’ has been described as a preferred phrase due to the word being *“less stigmatising, and it reflects that these individuals have not only disabilities which require a medical diagnosis, but also areas of cognitive strength”* (Baron-Cohen et al., 2009, p.500).

As the purpose of this research is to gain understanding of social media use amongst young people with ASC through directly eliciting their views, it is important to consider the potential impact of the diagnostic label and terms selected. This is why adopting the term ASC, rather than ASD, moves away from seeing autism as a ‘disorder’; instead suggesting autism represents a naturally occurring difference in thought patterns. For the purposes of this research, the word ‘condition’ is more congruent with a sensitive, respectful view of differences experienced by those with autism, so ASC will be used. ASC is a condition that can be described by a dyad of impairments; persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). These symptoms must have been present during the early

developmental period with three different levels outlined in the DSM 5 (American Psychiatric Association, 2013). Severity levels are outlined in table 1 below;

Table 1: Severity levels of autism; social communication and restricted interests/repetitive behaviours

| Severity level of ASC | Social Communication | Restricted interests and repetitive behaviours |
|------------------------------|---|--|
| Level 3 | Severe deficits in verbal/nonverbal social communication skills. Minimal response to social advances from others. | Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours. |
| Level 2 | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal response to social overtures from others. | Inflexibility of behaviour, difficulty coping with change or other restricted / repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. |
| Level 1 | Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. | Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |

(American Psychiatric Association, 2013)

For the purposes of this study, I will be focusing on ‘Level 1’, the higher functioning end of ASC. Generally, it can be assumed this population have an average level of intelligence (Frith, 2004).

1.2.2 Neurodiversity

Neurodiversity has been described in the Oxford Dictionary as (Oxford University Press, 2016) as *“the range of differences in individual brain function and behavioural traits, regarded as part of normal variation in the human population (used especially in the context of autistic spectrum disorders).”*

Similarly, neurodiversity has been described as a movement that *“challenges the medical model’s interest in causation and cure, celebrating autism as an inseparable aspect of identity”* (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Advocates for neurodiversity would like to see an emphasis on professionals in *“providing better support and acceptance for these individuals who already struggle with the condition versus persistently searching for what causes the ‘disability’ to arise”* (Walker, 2017, p.ii).

Neurodiversity is based around celebrating difference and providing ‘reasonable adjustments’ where appropriate, as opposed to searching for a ‘cure’ (Baron-Cohen, 2017).

Historically, the medical model was the dominant model used when treating disabilities, and was described, outlined and pioneered by professionals (Longmore & Umansky, 2001). In comparison, the social model (which neurodiversity emerged from) was a direct response in the 1970s from a group of individuals with disabilities who were unhappy with the application of the medical model (Centre for Disability Studies, 1976).

The medical model places responsibility and ownership of impairments on the person with the disability, and therefore all the solutions must be focused around the individual.

It has been argued that this provides a narrow perspective from which to understand disability, as factors that have some degree of impact on disability and its diagnosis, such as environmental and economic variables, are disregarded (Emerson & Hatton, 2007).

Although the World Health Organisation initially recommended diagnosis using the medical model which hypothesised that ASC is caused by genetic defects or environmental harm (World Health Organization, 1976), in 2001 the criteria for defining disability extended to include three components; impairments, activity limitations and participation restrictions (World Health Organisation, 2017). Therefore, the medical model has had to acknowledge that exclusion can be caused by society, and that this can contribute to the experience of disability along with systematic barriers and negative attitudes. This acknowledges a core element of the social model - which is society's failure to adapt to a person's differences that contributes to the disability. It has therefore been argued that this development has contributed to the medical model of disability becoming an outdated concept (Shakespeare & Watson, 2001).

The neurodiversity movement

Kapp et al. (2013) described how prior research has shown that young people can struggle with being 'different'. Furthermore research has suggested that those with ASC frequently experience loneliness and little belonging (Humphrey & Lewis, 2008; Huws & Jones, 2008; Ruiz Calzada, Pistrang, & Mandy, 2012) with some wishing for a 'cure' (Bagatell, 2007).

However the neurodiversity movement arose as a response to organised groups that were run by parents which were felt to be marginalising to people with autism, due to the emphasis on the medical model and search for a 'cure' within these groups (Ortega,

2009). The neurodiversity movement sought to create a community of people who can provide mutual support, self-advocacy as a community and a celebration of neurological difference. Neurodiversity argued that autism should not be viewed “*as an error of nature*”, rather “*a strange gift from our deep past, passed down through millions of years of evolution*” (Silberman, 2015; p. 470).

It is felt by the neurodiversity community that its role has not fully been recognised by medical professionals or advocates in the field (Cascio, 2012). The championing of neurodiversity has been hypothesised to have a positive impact on development of identity, with research suggesting that those who found an explanation for their ‘atypicality’ through understanding of neurodiversity were more able to develop a more valued self-concept (Tan, 2018).

Kapp et al., (2013) found an association between awareness of neurodiversity and a positive view of the autism identity. Having a positive view of autism has frequently been shown to have a positive impact on the families supporting a child with ASC (Russell & Norwich, 2012).

Therefore if a person with autism has achieved a life that is happy, productive and independent, they may be considered recovered as per the medical model (Baker, 2011), but living adaptively due to their autism being understood by the social model (Mackenzie, Cologon, & Fenech, 2017).

I will now discuss how individuals come to develop an ASC identity, through formal or self-diagnosis.

1.2.3 Diagnosis

ASC is described as a developmental condition that emerges over time which can be identified through behavioural observation (Ozonoff et al., 2010). ASC can now be diagnosed by the age of two with a good level of reliability, with the majority of diagnoses being made by the age of four (Mandell, Novak, & Zubritsky, 2005).

Researchers have noted that often when parents are given the diagnosis for their child, the child will not be present (Brogan & Knussen, 2003), which has left some parents with a dilemma of when it is appropriate to disclose the diagnosis to their child (Smith, Edelstein, Cox, & White, 2018). It has been noted by parents how overwhelming this process can be (Carlsson, Miniscalco, Kadesjö, & Laakso, 2016), particularly given the complexity of the diagnostic process (Crane, Chester, Goddard, Henry, & Hill, 2016).

Similarly scholars have noted how the label of ‘autism’ must be understood within a social constructionist perspective and that an individual’s interaction with the environment is the cause of many observable behaviours that inform diagnosis (O’Reilly & Lester, 2017). Some have argued that there are many advantages of diagnoses, including a sense of self-acceptance, having access to strategies which can result in quality of life improvement, and the ability to attain and maintain a sense of normalcy (Lewis, 2016).

1.2.4 Self-diagnosis

As understanding and acceptance of neurodiversity in society emerges, an increasing number of individuals have chosen to self-diagnose as having autism, rather than go through the complex diagnostic processes, which often involve extensive behaviour observations to determine if the person reaches the criteria for ASC as outlined by the DSM-V (Sarrett, 2016).

Some members of the ASC community have been apprehensive about the emergence of ‘self-diagnosed’ individuals, with some going as far as not recognising those who have not been through a diagnostic process (Sbaffi & Rowley, 2017). Some have worried about the increasing number of individuals with a self-diagnosis as they may feel that the experiences of those with a diagnosis are different to those without. It is felt by some that this is particularly prevalent for young people online, as it has been argued there is a large amount of misinformation available on the internet (Sbaffi & Rowley, 2017).

However many others fully accept self-diagnosis, arguing that if one recognises themselves in terms of how ASC has been described, then you should be welcomed into the autistic community (Sarrett, 2016).

A participant in Sarrett’s (2016) study who self identified as an individual with ASC noted;

“Self-diagnosing has given me some peace of mind about my own behavior and quirks (for lack of a better term). That’s all. No one else has to accept that it’s really true - it’s simply true enough for myself. I am not looking for special treatment - in fact, quite the

opposite: having labeled myself with AS[C] enables me to check myself and adapt to daily living far better than if I didn't know.” (Sarrett, 2016, p. 31).

Similarly Wylie (2014) emphasised the importance of both formal and self-diagnosis and its potential impact on the mental health of those with ASC;

“It is very difficult for the late-diagnosed [person with ASC] to not to feel ‘broken’ following self-identification, especially if we don’t have access to significant emotional, financial and therapeutic support. ... Without appropriate post-diagnostic [including self-diagnosis] support during the identity alignment stage, our mental health is likely to deteriorate.” (Wylie, 2014, p. 46 as referenced in Lewis, 2016).

For professionals working with those who have self-diagnosed, Lewis (2016) emphasised the importance of exercising caution before writing off any self-diagnosis;

“Self-diagnosis should not be refuted until carefully considered, and professionals should recognize that adult presentations of [ASC] may appear different than childhood presentations of [ASC] due to learned coping mechanisms.” (Lewis, 2016, p.2123).

Similarly those who self-identify as an individual with ASC and have a high awareness of neurodiversity have been shown to be more likely to see ASC as a positive thing that needs no cure (Kapp et al., 2013).

This research will be looking to explore the lived experiences of those with ASC and their interaction with the online world. Therefore, neurodiversity will be acknowledged as important particularly given its relevance to social media (as neurodiversity emerged online). Similarly, if someone has chosen to self-identify as having autism, their experiences will be explored alongside those with a formal diagnosis.

I will now discuss gender and how it relates to the lives on young people with ASC.

1.2.5 Gender

There is a reported gender difference between males and females with autism, as there is a higher number of males than females with autism (Simon Baron-Cohen, 2002; Ehlers & Gillberg, 1993; Knickmeyer, Wheelwright, & Baron-Cohen, 2008; Lord & Schopler, 1987). One review suggested that the ratio is 4.3:1, which will increase to 9:1 for those with a lower severity of ASC (e.g. level 1, see table 1; Rivet & Matson, 2011).

This reported difference has had a significant impact on both research and work for practitioner psychologists as has the difference between gender and sex. As defined by the online APA Dictionary of Psychology, the difference between gender and sex is outlined as follows;

“Sex usually refers to the biological aspects of maleness or femaleness, whereas gender implies the psychological, behavioral, social, and cultural aspects of being male or female (i.e., masculinity or femininity.)” American Psychological Association (2015a)

For the purposes of this paper, I will refer to ‘gender’ to acknowledge that it is a psychological, behavioural, social and cultural construct, whilst acknowledging its importance with regard to identity development.

Research has shown that generally women score higher than men when it comes to internalising conditions such as anxiety or depression (Bogren, Brådvik, Holmstrand, Nöbbelin, & Mattisson, 2018; Gater et al., 1998; Hankin, 2009; Macleod, Macmillan, & Norwich, 2007). Similarly, women with ASC appear to show higher levels of internalising conditions (Cai, Richdale, Dissanayake, & Uljarević, 2018). Some research has suggested males are more likely to engage in externalising behaviours such as hyperactivity, aggression or rule breaking (Boyd et al., 2015; Matos et al., 2017),

which can be associated with externalising behaviours (behaviours that are directed towards others) such as hyperactivity, aggression or rule breaking , or conditions such as Attention Deficit Hyperactivity Disorder or Oppositional Defiant Disorder (American Psychiatric Association, 2013). However it is unclear from the current research whether males with ASC are more likely to show externalising conditions (Cai et al., 2018; Shea, Payne, & Russo, 2018), although it is important to note that those with ASC generally show higher rates of externalising behaviours (Shea et al., 2018).

Due to the higher numbers of males in the ASC population (Baron-Cohen, 2002; Ehlers & Gillberg, 1993; Knickmeyer et al., 2008; Lord & Schopler, 1987), some researchers have raised concerns that underrepresentation of females (which has been long-standing in ASC based research) has created a male-based understanding of what ASC is (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015).

Unpicking the gender difference within the ASC population has proven to be complex and difficult. This difficulty was summarised by Lai et al., (2015) as

“[The] findings from different studies are complex and do not always relate to each other in a straightforward manner. This is because there are several different (but interlinked) questions embedded in the broad theme of the relationships between sex/gender differences and autism. For instance, asking “Do females with autism have different behavioral characteristics from males with autism?” is different from “Why are there more males diagnosed with autism?” or “Why are males more susceptible to developing autism?” These questions may be interlinked but require different methodologies to address them.” (p. 11-12)

There does appear to be a difference in ASC characteristics for men and women, with one meta-analysis reporting that there is a different set of observable characteristics for females with ASC (Lai et al., 2015). It is argued by some researchers that there needs to be further research into this difference, to develop appropriate instruments to detect and ascertain the traits within the female ASC population (Van Wijngaarden-Cremers et al., 2014).

Gender Identity/transgender dysmorphia

There is emerging research on those with gender identity disorder or ‘transgender dysmorphia’ (Hepp, Kraemer, Schnyder, Miller, & Delsignore, 2005; Toomey, Ryan, Diaz, Card, & Russell, 2010). Please see table 2 below for definitions of those who may be described as having ‘gender dysmorphia’, as defined by the American Psychological Association Dictionary of Psychology (2015) and the Guidelines for Psychological Practice With Transgender and Gender Nonconforming People (American Psychological Association, 2015b):

Table 2: Gender Identity/transgender dysmorphia definitions

| <i>Term</i> | <i>Definition</i> |
|--------------------------|--|
| <i>Genderqueer</i> | <i>A term to describe a person whose gender identity does not align with a binary understanding of gender (i.e., a person who does not identify fully as either a man or a woman). People who identify as genderqueer may redefine gender or decline to define themselves as gendered altogether. For example, people who identify as genderqueer may think of themselves as both man and woman (bigender, pangender, androgyne); neither man nor woman (genderless, gender neutral, neutrois, agender); moving between genders (genderfluid); or embodying a third gender.</i> |
| <i>Transgender man</i> | <i>Also known as trans man or transman: a person whose sex assigned at birth was female, but who identifies as a man.</i> |
| <i>Transgender woman</i> | <i>A person whose sex assigned at birth was male, but who identifies as a woman.</i> |

Gender dysmorphia is described as “*mismatch, or incongruence, that one may have about one’s experienced gender versus one’s assigned gender*” (American Psychological Association, 2015a). Transgender dysphoria is the “condition of feeling one’s emotional and psychological identity as male or female to be opposite to one’s biological sex” (Oxford University Press, 2018).

Reports of the percentage of the population who identify as genderqueer vary (Richards et al., 2016) as do statistics around those who identify as transgender. However it was recently reported in the USA to be around 0.6% of the population (Flores, Brown, & Herman, 2016). It appears that the number of youth presenting for treatment is increasing rapidly (Cartaya & Lopez, 2017).

This group have been shown to experience higher levels of depression and anxiety disorders, while reporting lower life-satisfaction (Murad et al., 2010). One study exploring the impact of gender dysmorphia and ASC found that gender dysphoria was highly correlated with lower levels of well-being (George & Stokes, 2018).

There are reports of a high level of co-occurrence between those with ASC and gender dysmorphia (Kraemer, Delsignore, Gundelfinger, Schnyder, & Hepp, 2005; Mukaddes, 2002; Strang et al., 2018). Similarly, there are reports that suggest an association between gender dysphoric traits and ASC (George & Stokes, 2016; Jones et al., 2012; Pasterski, Gilligan, & Curtis, 2014; Strang et al., 2018).

Theories as to why there is co-morbidity have been explored. For example, it has been hypothesised that difficulties in Theory of Mind (ToM; Baron-Cohen, Leslie, & Frith, 1985) coupled with difficulties with ambiguity (cognitive rigidity; which is a common characteristic in individuals with ASC), may lead to difficulties in gender identity formation and consolidation (Jacobs, Rachlin, Erickson-Schroth, & Janssen, 2014). However a recent review suggested that there is little statistical evidence to support this theory (van Schalkwyk, Klingensmith, & Volkmar, 2015).

I will now discuss how social interaction and social support impact on the lives on young people with ASC.

1.2.6 Social interaction and social support in ASC

It has been argued that the needs of many individuals with higher functioning ASC go unnoticed, due to the masking of needs in straightforward social situations (Marian, Sigman & Capps, 1997), e.g. by often having fewer difficulties with language.

Difficulties with social interaction can create problems at school and beyond. For example, individuals with ASC frequently struggle compared to a typical population in terms of gaining and retaining employment (D Hedley, Uljarević, Cameron, & Halder, 2016). Unemployment is associated with low levels of psychological well-being and mental health problems (McKee-Ryan, Song, & Wanberg, 2005; Paul, Vastamäki, & Moser, 2016). However, a recent meta-analysis has argued that the research literature was limited due to poor participant characterisation, small sample size and/or a lack of randomisation and use of appropriate controls (D Hedley et al., 2016). This meant that findings were limited in quality; therefore interpretation of the findings is less reliable. It was noted that future research must employ a more multidisciplinary and multifaceted approach to exploring employment and how it affects each individual.

There are indications that poor social support is linked with a range of mental health problems and poor life outcomes (Rosenblatt, 2008). Access to a strong social support network has been shown to be a strong determining factor in the well-being of people with ASC (Renty & Roeyers, 2006). It is unclear from the literature whether support networks involving direct contact with others are protective, or whether online support networks through social media could have similar positive influence on well-being.

I will now discuss digital media and how young people (with and without ASC) operate within the digital world.

1.2.7 Digital media

It is reported that young people with ASC spend an increased amount of time using digital media than their typically developing counterparts (Montes, 2016; Shane & Albert, 2008), yet proportionally less time on social media (Mazurek, Shattuck, Wagner, & Cooper, 2012; Mazurek & Wenstrup, 2013). Some research has found up to 98% of adolescents with ASC spend an average of five hours a day on the computer (Kuo, Orsmond, Coster, & Cohn, 2014). This has led to significant concerns due to research that has shown social media use to be related to depression, social isolation and cyber-bullying (O’Keeffe & Clarke-Pearson, 2011). Young people with ASC are typically at higher risk of a range of mental health problems, so the potential of high levels of social media use exacerbating this vulnerability is hotly debated (Müller et al., 2008; Schroeder et al., 2014). It does appear that there are mediating factors to protect those most vulnerable against these vulnerabilities, for example using the internet less frequently and access to tangible support (Darren Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2017; Kraut et al., 1998). Other mediating factors include parental mediation (e.g. talking to their child about internet use, parental blocks of websites), teacher mediation, taking advice from friends and receiving guidance on how to manage the online world (Sonia Livingstone, Haddon, Görzig, & Ólafsson, 2010).

However, there is currently a paucity of research relating to the views of young people with ASC on their use of social media and whether they self-identify online (do they identify as an individual with ASC; or do they feel they can operate like a ‘typical’ adolescent due to the different medium of interaction). It is also unclear how friendships are viewed and whether relationships that develop are considered more or less valuable online. Furthermore, as job opportunities become more digital and less face-to-face, is

the immersion of digital media a force for empowering the ASC community in gaining and retaining employment? In the following section there will be four main areas of focus; digital identity, relationship formation, psychological well-being and life outcomes.

1.2.8 Development of identity

An individual's sense of identity continues to develop during adolescence (Erikson, 1968). It has been reported that when adolescents have ideas and feelings about themselves, they will merge to form a perception of identity (Adamson & Lyxell, 1996), a construct that has been a foundation of psychological debate for many decades (Berzonsky, 1989; C. R. Cooper, Grotevant, & Condon, 1983; Cote & Levine, 2014; Grotevant & Cooper, 1985; Marcia, 1966; Schwartz, Côté, & Arnett, 2005; Schwartz et al., 2005). It has also been stated that;

"Identities are the traits and characteristics, social relations, roles, and social group memberships that define who one is." (Oyserman, Elmore, & Smith, 2012, p. 69)

Research has progressed into understanding elements of identity and how it can manifest in different ways, for example identification (or lack of identification) with a minority group (Grotevant, 1992).

Berry, Trimble, and Olmedo (1986) outlined four different types of acculturation to an identity of a minority group. Acculturation involves maintaining their cultural customs and having relationships with others from their minority group (Schwartz & Zamboanga, 2008);

- *Assimilation: acquires the receiving culture (a culture for which they may not typically be expected to be part of) and discards the heritage culture (the culture they would typically be apart of).*
- *Separation: rejects the receiving culture and retains the heritage culture.*
- *Integration: acquires the receiving culture and retains the heritage culture.*
- *Marginalization: rejects the receiving culture and discards the heritage culture.*

This theory of acculturation was adapted for the purpose of being applied to minority ethnic groups (Berry, 1997). Instruments developed to appraise identity in minority ethnic groups have been adapted for use with other minority groups such as individuals with hearing impairments or autism (Glickman & Carey, 1993; Jarrett, 2014; Maxwell-

McCaw & Zea, 2011). An example of this is the Deaf Acculturation Scale (DAS; Maxwell-McCaw & Zea, 2011), which is a measure of deaf acculturation over five areas (cultural involvement, cultural knowledge, language competence, cultural identification, and cultural preferences). The DAS has been adapted and used in other studies as a measure of autism acculturation (Jarrett, 2014).

It is so far unclear from the research whether young people with ASC's identity development is congruent with a 'typical' adolescents development (as outlined by Marcia et al., 1993). Moreover, the extent to which young people with ASC are at any particular stage i.e. assimilation, separation, integration or marginalisation (as outlined by Schwartz & Zamboanga, 2008) with the ASC community is difficult to discern, in particular with regard to how this differs online and offline. It is also unclear whether a minority group such as those described with ASC is something that an individual can choose to identify as, or whether it is something that is always based on experiences. For the purposes of this research, I have chosen to include all of those who identify as an individual with ASC (including those who self-diagnose, see section 1.2.4) and understand their experiences as a whole group. Although self-report is at risk of bias, there is a growing research base into ASC identity that must be further explored.

1.2.9 ASC Identity

There have been several recent publications regarding how an ASC diagnosis influences identity development (Cox et al., 2017; Laurelut, Latif, Billington, Simon, & Hassall, 2016). Although there are still reported tensions between their public and private identities (Cox et al., 2017), anecdotally it appears there are ever-increasing platforms for people with ASC to discuss identity (Feedspot, 2017), with a greater understanding that many view autism as naturally occurring difference in thought as opposed to the diagnosis representing a ‘disorder’ (Sullivan, 2017).

It does appear at this point there is less research regarding autism identity than for other minority groups. Some researchers have suggested this is due to a deficit view of the condition (Bagatell, 2007). However some older research described the key to identity development as being rooted in social perspective taking (Enright & Deist, 1979), for example being able to understand a situation from another’s perspective. This is known as ‘Theory of Mind’, which is considered to be one of the key areas of difficulty for individuals with ASC (Baron-Cohen et al., 1985).

For many, a condition represents an important aspect of their identity and this can act as a protective mechanism, raising levels of individual and group self-esteem (Cooper, Smith, & Russell, 2017). The empirical research has also shown that individuals with ASC are more likely to be happy in a relationship with another person with ASC as opposed to someone without ASC (Strunz et al., 2017).

For some individuals, they may be reluctant to accept ASC as a part of their identity, while they may strive to hide their ASC, or appear ‘normal’ (Humphrey & Lewis, 2008). They may also distance themselves from any label (Cooper et al., 2017) and some may search for a cure (Bagatell, 2007). However, rejecting ASC as any element of identity

does appear to be associated with lower levels of psychological well-being (Cooper et al., 2017).

A recent study has stated that individuals with ASC are less likely to be involved with groups in the mainstream community. It has been argued that identifying with ASC can provide a sense of valued identity and belonging, which can contribute to reduced social anxiety, which in turn can increase social skills and opportunities to form new friendships (Baxter, 2018).

It has also been suggested that autism may not be viewed in society as a valid identity, which can be demonstrated by the use of therapeutic interventions that aim to lower behaviours described as 'deviant'. This could be a cause for individuals with ASC wanting to hide their identity. However this is an ever-changing field which has been challenged by many advocates for neurodiversity, who see ASC as atypical neurological development, which should be viewed as a normal human difference (Jaarsma & Welin, 2012).

1.2.10 Digital Identity

Social networking sites have been described as virtual communities of people that can carry expectations of sociability, meaningful connections, conviviality or even empathy and support (Parks, 2011). Within these virtual communities, the creation of an online profile coupled with the formation of new social networks will impact directly on how an individual presents themselves (Greenhow & Robelia, 2009). Social media has also allowed young people to create an identity and image of how they see themselves and how they want others to see them (Williams & Merten, 2008). Williams and Merten (2008) argued that online networks provided a safe place for self-expression, where:

“Adolescents who feel they have lost their voice or are unheard by authority figures in their personal lives can channel their energy and need for attention into their online journal, versus feeling confused, worried, negative, misunderstood, or physically acting out.” (2008, 257; as referenced in Greenhow & Robelia, 2009, p.124).

Social networking is a relatively new social medium that is accessed regularly by children from around aged 8 and above (Eynon & Malmberg, 2011). The ways that children interact with social networking may therefore play a vital part in the formation of identity, however it is still unknown what impact social networking will have on identity due to the online world being a relatively new environment (those reaching early adolescence in the early 21st century are currently one of the first generations to have grown up with it). It is clear however that the nature of young people’s interaction with social media could have a significant effect on their thoughts and information processing (Prensky, 2001). Similarly personal-construct psychology argues that

nothing is free from the interpretations that we as individuals place on them, therefore identity is affected by the systems that we use to interact (Kelly, 1955; Landfield, 1980).

When addressing modern adolescents' preferences for social media, Boyd (2007) outlined four properties of identity formation in a social media setting, which differ from identity formation in a social setting:

1. ***"Persistence:** Unlike the ephemeral quality of speech in unmediated publics, networked communications are recorded for posterity. This enables asynchronous communication, but it also extends the period of existence of any speech act."*
2. ***"Searchability:** Because expressions are recorded, and identity is established through text, search and discovery tools help people find like minds. While people cannot currently acquire the geographical coordinates of any person in unmediated spaces, finding one's digital body online is just a matter of keystrokes."*
3. ***"Replicability:** Hearsay can be deflected as misinterpretation but networked public expressions can be copied from one place to another verbatim such that there is no way to distinguish the "original" from the "copy.""*
4. ***"Invisible audiences:** While we can visually detect most people, who can overhear our speech in unmediated spaces, it is virtually impossible to ascertain all those who might run across our expressions in networked publics. This is further complicated by the other three properties, since our expression may be heard at a different time and place from when and where we originally spoke."* (p. 126, Boyd, 2008)

Although these four properties were hypothesised over ten years ago and the nature of internet use will have changed for young people, it could be argued that persistence, searchability and replicability could assist in making the nature of social communication online more concrete and unambiguous. Therefore, this could potentially create an area in which young people with ASC could find social communication more straightforward.

Greenhow and Robelia (2009) outlined how in a world where young people are increasingly connecting with peers online, the four characteristics outlined by Boyd (2008) present educational risks and benefits. This warrants provision and guidance by those working with young people to develop their awareness of the benefits and pitfalls.

Social media may also be offering young people opportunities to explore aspects of their identities that they were previously not able to (Boyd, 2014; Dunkel, 2000). For example, a sample of typically developing children have become engaged in online communities that involve peer to peer interactions on political or civic websites (Couldry, Livingstone, & Markham, 2016; Livingstone, Bober, & Helsper, 2005).

Others have argued that much of the population view the online world as a phenomenon where “*whoever is not available on the internet does not exist*” (p. 138), and people are quick to create alter egos of themselves (Feher, 2015). Would a phenomenon in this vein create an environment where people with ASC do not identify as individuals with ASC online? The next construct to be explored is ASC online identity.

1.2.11 ASC Online Identity

A comprehensive literature search revealed the paucity of research into online identity for children with ASC.

Some research that has focused on a more medical view of disability (e.g., physical disability) found through qualitative analysis that individuals revealed their disability depending on the demands of the context and relevance of the disclosure (Anderberg & Jönsson, 2005).

Some more historical research reports (from when the internet was first in use), described the internet as a ‘safe’ place, where individuals can network with other people from the ASC community (Dekker, 1999). It can be postulated therefore that the internet could provide an environment to encourage identity development, although the outcomes of this are unclear from the evidence provided.

One study found that people with Down syndrome used social media as a place to “*construct and present multiple selves: a self that is similar to those with Down syndrome and a self which is also different*” (Seale, 2001, p. 349). It was hypothesised that social media supported individuals in accepting Down Syndrome as part of their identity, whilst denying the social stigma that comes with a condition, allowing them to build an identity that is different (Benford, 2008).

It is noted by Brownlow and O ’Dell, (2006) in their final conclusions; “*We propose that the Internet is a useful tool in enabling individuals with autism to share their experiences and perceptions of the label ‘autism’ and have these perceptions and experiences recognized within a professionally dominated discourse of autism.*” (p. 320)

Although the research is over ten years old, the findings were ascertained through posts from young people with autism in internet chatrooms. This highlights the importance of understanding ASC identity via the experiences of people with ASC themselves. It must be noted that presenting opinions in this way has social power, but may be an unreliable means of ascertaining representative views due to the fact that participants hold perspectives that they disseminate using the internet, as this is a useful vehicle for promoting the rights of those with autism (see section 1.2.2 on p.19). These findings should be treated with caution as the context of online debates means that publicised perspectives may not be held widely within the ASC population. For findings to hold rigour, a multi-faceted approach to ascertaining views is necessary.

Furthermore, as a relationship has been previously noted between internet use and loneliness (Kraut et al., 2002; Shillair et al., 2015; Skues et al., 2016; Zhao, 2006), the next step will be to review the literature on relationship formation for adolescents, and how relationship formation may be different for children with ASC.

1.2.12 Relationship Formation

Relationship formation is a skill that serves many important functions across one's life, with some calling it a core human need (Erwin & Phil, 1993; Sullivan, 2013). It has also been shown to be central to social development, which is inter-related with other areas, such as physical health (Allen, Uchino, & Hafen, 2015; Mikami, 2010).

The functions of school-age friendships have been hypothesised to be fulfilling a life-long need for social connectedness and develop friendships. There are significant potential negative consequences if this need is not met (Baumeister & Leary, 1995; Rueger, Malecki, Pyun, Aycok, & Coyle, 2016). Klinger (1977) found that children view friendship as one of the most important things in their life (as cited in Mendelson et al., 2016).

The purpose of friendships has been hotly debated for many years going back to ancient Greek times with Aristotle hypothesising that there are three different types of friendship (Walker, 1979); with the first being based on usefulness, where both people derive benefit from each other. The second type of friendship based on pleasure, where both people each other's qualities (e.g. sense of humour). The third type of friendship is based on 'goodness', where both friends admire each other's goodness and help them strive for it. More recent research has found the purpose of friendship to be related to other factors, for example emotional support, positive interactions, coercive power, and conditional social regard (Ferguson, Duffy, Zimmer-Gembeck, & Laursen, 2018).

To fully understand the processes and functions of friendship formation for children with ASC, one must look for the purpose of friendships for typically developing children (e.g. reduction of risk due to safety in numbers, social support).

See figure 1 for a model of friendship which has been defined by two processes; surface level activities and deep structured reciprocity. The model was designed to reflect how friendships manifest throughout different stages in one's life. These stages are described as:

- **Surface level activities** are behaviours that you would expect to see from a child in that setting, stage of development and within that culture.
- **Affective sharing** is when a child develops the ability to understand subtle social cues, then moderate their own facial expression, body posture, vocal intonation, verbal statements, and gestures to respond. It is this process that leads to deep structure (Mendelson et al., 2016).
- **Deep structure reciprocity** is developed through engagement in surface level activities. Children will develop deep structure reciprocity of friendships.

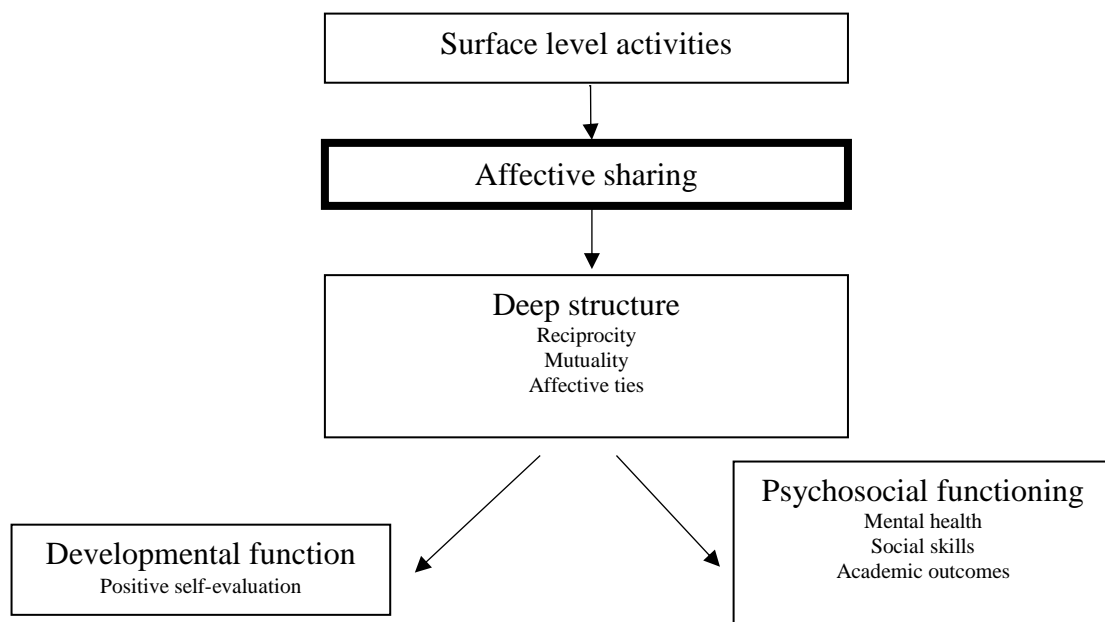


Figure 1: The processes and benefits of friendship for typically developing boys aged 8-12 (Mendelson et al., 2016; derived from Hartup and Stevens 1997).

From this model and the skills outlined in affective sharing, it is hypothesised that the area of difficulty for children with ASC is related to the affective sharing function, as children with ASC often experience difficulties understanding subtle social cues, facial expressions, body language, and vocal intonation.

It is important to note that this model was hypothesised for boys aged 8-12, so there may be some missing elements with regard to friendships in girls or adolescent boys. This is due to the fact that gender differences in friendship patterns are evident from the pre-school period (e.g. boys tend to choose physical play and boisterous activity, girls tend to prefer familiar role play), and by the time they are at primary school, children show preferences for same-sex friendships. Although friendships within both genders share features, there are fewer opposite sex friendships, which has indicated a difference between relationship formation for males and females. Researchers have hypothesised that this is related to gender norms (Al-Attar et al., 2017).

The adolescent period is also important in developing self-worth. Friendship has shown through research to be vital in terms of an individual's development of feelings of a positive self-image and self-competency (Hartup & Stevens, 1997). The development of these friendships is also important when evaluating the processes involved in self-validation and evaluation, which in-turn contribute to a feeling of self-worth (Brooks, 2015; Gauze, Bukowski, Aquan-Assee, & Sippola, 1996; Liu & Baumeister, 2016; Monks & Maunder, 2014; Robinson, 1995; Shany, Wiener, & Assido, 2013), which can have a positive impact on well-being. The difficulty experienced by children with ASC in forming relationships could explain why they are at higher risk of low-self-esteem.

1.2.13 Relationship formation for ASC

The ability to form friendships is well-established as an area of difficulty for children with ASC (American Psychiatric Association, 2013). The vast majority of individuals with ASC do show interest in forming both friendships (Mendelson et al., 2016) and romantic relationships (Strunz et al., 2017). Although a recent meta-analysis with 1,768 participants found young people with ASC are able to form good quality relationships with their peers and parents, self-reported friendship quality and parent/peer reported quantity was reported as lower than typically developing peers (Mendelson et al., 2016). This was a medium to large effect with no significant variation across studies.

Furthermore, children with ASC are at increased risk of social isolation, peer victimization, and friendlessness (Deckers, Muris, & Roelofs, 2017; Mendelson et al., 2016; E Van Roekel, Scholte, & Didden, 2010; Ung et al., 2016).

Young people with ASC have frequently shown to have fewer social interactions when compared to their peers of the same age (Candini et al., 2017; Clay, Samaha, & Bogoev, 2017; Lord & MaGill-Evans, 1995). Research has shown that there is a relationship between social difficulties and well-being (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017; Vickerstaff, Heriot, Wong, Lopes, & Dossetor, 2007; S. W. White & Roberson-Nay, 2009), although some recent research has refuted this (Hollocks et al., 2014).

Research has shown that the quality of friendships is associated with a sense of self-worth (Kingery, Erdley, & Marshall, 2011; Mendelson et al., 2016). Friendships have also been shown to discourage norm violations that can predict future anti-social behaviour, whilst encouraging norms and providing opportunities to develop social competency (Hartup, 1995; Mendelson et al., 2016). Furthermore, figure 1 highlights

that friendships are an important part of psychosocial development (including mental health, social skills and academic outcomes).

Research has shown that adolescents with ASC can be capable of forming relationships independently (Bauminger, Shulman, & Agam, 2004). Although many children with ASC struggle with peer relationships at schools, one study reported that 20% of a sample of 60 children with ASC had at least one reciprocated friendship and high social network status (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011). Therefore, difficulties with friendships do not affect all children with ASC, although most experience some level of distress regarding social relationships.

It has been suggested that access to typically developing peers and normal social settings can benefit in achieving social outcomes for children with ASC (Kasari et al., 2011; Sigman et al., 1999). Furthermore, other research has suggested that children with ASC are likely to engage socially with typically developing peers, as opposed to peers with special educational needs (Bauminger, Shulman, & Agam, 2003). Research ascertaining parents' views has found that if they perceive their child with ASC as having an inclusive experience at school, the child is more likely to achieve peer acceptance and be able to form meaningful friendships with their classmates (Ryndak & Downing, 1995; Staub, Schwartz, & Gallucci, 1994).

A recent meta-analysis performed by Mendelson et al. (2016) found from a range of 18 papers with 1,768 participants (aged 8-12), that children with ASC had significantly lower sociometric status (the degree to which someone is liked or disliked by their peers) than their typically developing peers. Most young people with ASC had at least one friend across all studies, yet the number of friends significantly varied across participants. However young people with ASC had significantly less social connections than typically developing peers and had fewer reciprocal friendships. Young people

with ASC were less likely to appear in other students “top three friends in the class”, self-reported friendship quality was poorer.

It is noted that all this research was conducted using survey methodology (from parent, self and peer report). Although there are advantages of this type of research design such as ease of administration, there are a wide range of disadvantages relating to representativeness such as;

- Social desirability responses, where participants may provide a response that they see as socially desirable, rather than true.
- Validity of data, where it may be difficult to ensure that the questions posed are measuring what it is intended to measure.
- Lack of clarity of questions and potential error of questions, where questions are not clear to the participant and an inaccurate response is given.

Therefore, it must be understood that there may not be a deeper level of exploration that could be found through a qualitative approach, as many of these findings are context dependent.

The important point from this meta-analysis is that although children with ASC typically experience fewer friendships from sociometric, parent, and self-report measures, young people with ASC are capable and do make friends. These findings also appear to be robust against publication bias, meaning the research on friendship formation for young people with ASC appears to be a reflection of the experiences of the ASC population, rather than specific pieces of research being chosen for publication due to favourable results being found.

Other researchers have looked to implement interventions for young people with ASC that aim to facilitate skills that can help young people with autism establish friendships. For example, Bauminger (2002) implemented an intervention for a group of children, based on the principles of Cognitive Behavioural Therapy. A number of improvements were noted following the intervention; increased likelihood of initiating conversation or

eye contact, further ability to share experiences and increased interest in peers. This demonstrates that the difficulties young people with ASC may be experiencing may be due to the social expectations that come with operating within a neurotypical world (e.g. eye contact, social etiquette) and to support these young people to adapt to this world. Similarly, it is important to note that young people with ASC may not require the same type of relationships that we expect as 'neurotypical' individuals. Although the evidence suggests that young people with ASC can and want to make friendships (Bauminger et al., 2004), they may not necessarily need to be on the same terms as someone without ASC. A person with ASC may have their needs met in terms of what they seek in friendships through social communication in a different way. Therefore, young people with friends that they do not see face to face, but frequently interact with via phone or internet may be perfectly happy with this type of friendship and not seek friendships that require face-to-face interaction.

The next area to be explored is how relationship formation over social media is different or similar to relationship formation through face-to-face interaction, with a particular focus on individuals with ASC.

1.2.14 Relationship formation and social media

The emergence of social media has been reported to have a significant effect on the population with ASC, in a way some anecdotal reports have likened to the emergence of sign language in the deaf community (Blume, 1997). This is described by Blume (1997) as “*by filtering out the sensory overload that impedes communication among autistics, the Internet opens vast new opportunities for exchange*”. There are many real-life blogs that can be viewed, where young people with ASC are able to communicate their experiences (Autism Blogs Directory, 2015).

There have also been reports of ‘supportive relationships’ being formed (although there may be issues regarding who to trust, assessing information, and knowing what is appropriate to disclose or not; Burke, Kraut, & Williams, 2010). Some families have reported using social media as a tool to adapt to their child with a disability (or condition), improving family relationships (Nally, Houlton, & Ralph, 2000). There is little research on the ability of young people with ASC to perceive these positive benefits in themselves.

The impact social media has had on relationship formation for young people without ASC appears unclear at this time, particularly as “*Until recently, it would seem that analysis of children’s experiences, social relations and lifeworlds implicitly prioritised face-to-face, physically co-located communication as the primary means through which their everyday lives are constituted and, therefore, the primary means through which research with children is to be conducted*” (Christensen & James, 2017, p. 62). Some recent studies used within classrooms have found integrating face to face interaction with social media within a classroom environment has increased student interaction (Govaerts et al., 2018). It would appear that young people without ASC can experience

the benefits of online communication, however they do not experience 'sensory overload' in the same way a young person with ASC would, so may be able to communicate their experiences verbally as well as through social media.

Family relationships and social support structures can have a positive impact on the next area to be reviewed for those with and without ASC; psychological well-being (Drummond et al., 2016; Renty & Roeyers, 2006).

1.2.15 Mental health and psychological well-being for young people with ASC

A study from the USA has estimated that around 25% of young people or children will have had experiences of anxiety or depression by the time they enter adulthood (Copeland, Shanahan, Costello, & Angold, 2011). There are a range of factors and contributors that can lead to difficulties in achieving psychological well-being such as genetic, environmental and temperamental influences. It is also suggested that experiencing difficulty with social interactions can play a central role in the development of well-being (Rumney & Macmahon, 2016).

Psychological well-being for young people with ASC is a significant concern outlined by many autism support services, as around one in three adults with autism experience significant mental health difficulties (Autistica, 2017; National Autistic Society, 2017). Individuals with ASC have been found to have higher levels of social isolation, marginalisation from society and psychological problems, including low self-esteem, stress, anxiety and depression (Ghaziuddin, 2005).

Other studies have reported high levels of anxiety (50%), mood disorders (53%), ADHD (43%) and psychotic disorders (12%; Hofvander et al., 2009). A similar study found 44% from a sample of children with ASC were in the borderline to clinical range for depression and 56% to be in the borderline or clinical range for anxiety symptoms (Strang et al., 2012).

One study involving 7 to 13 year olds with ASC diagnosis found that depression levels increase with age and IQ (Vickerstaff et al., 2007). These findings have been supported by further research indicating higher cognitive functioning is related to increased levels of depression, with the prevalence increasing over time (Ghaziuddin, Ghaziuddin, & Greden, 2002). Therefore, children with an ASC severity level of one (see table 1) may

be the most at risk of mental health difficulties as they are likely to have higher cognitive functioning. It is also important to note that generally, mental health problems become more severe in the adolescent period and there is a high risk of continuation into adulthood (Merikangas, Nakamura, & Kessler, 2009).

It has been estimated that between 75% and 95% of autistic people have special interests, for example computers, autism, music, nature and gardening (Klin, Danovitch, Merz, & Volkmar, 2007; Turner-Brown, Lam, Holtzclaw, Dichter, & Bodfish, 2011). A positive link was found between motivation to engage with special interests and subjective well-being, along with satisfaction across specific life domains including social contact and leisure. However, a link was found between a high intensity of engagement with special interests and low levels of subjective well-being (Grove, Hoekstra, Wierda, & Begeer, 2018).

As described in the transactional development pathway model (Vasey & Dadds, 2001), if an individual experiences social difficulties repeatedly, it can lead to maladaptive coping skills developing, which can heighten the risk of anxiety. Then if the individual with the difficulties is interpreting or predicting the others behaviour, it will maintain the anxiety (Rumney & Macmahon, 2016). However, if young people with ASC experience fewer social difficulties in their online relationships, could this bring higher rates of psychological well-being for this at-risk population?

1.2.16 Psychological well-being and social media

For a typically developing population, social media has been shown to increase levels of social capital (networks of relationships among people who live and work in a particular society, enabling that society to function effectively; Oxford University Press, 2016) for young people, particularly for children with lower levels of self-esteem (Carmichael, Archibald, & Lund, 2015; Ellison, Steinfield, & Lampe, 2007; Steinfield, Ellison, & Lampe, 2008). Frequent users of social networking have also been shown to exhibit greater social trust, higher levels of civic participation (Choi & Shin, 2016; Skoric, Zhu, Goh, & Pang, 2015; Valenzuela, Park, & Kee, 2009), and higher levels of social bonding (Ahn, 2012; Burke et al., 2010).

The relationship between self-esteem and social media use is unclear, as it can often depend on how an individual is using social media (Valkenburg, Peter, & Schouten, 2006; Vogel, Rose, Okdie, Eckles, & Franz, 2015; Wood, Bukowski, & Lis, 2016). Some studies have concluded that social media has a profoundly negative impact on self-esteem or self-efficacy (Brooks, 2015). This is due to a range of factors, with Brooks (2015) describing the correlational relationship between type of stress unique to technology called technostress. It must be noted that there was no data collected on type/purpose of social media usage. Therefore, as previously outlined, the effect social media use has on well-being could be dependent on how an individual is using social media.

Social media has been shown to exaggerate social norms particularly in relation to body image; (Rost et al., 2016; Waskul, Douglass, & Edgley, 2000), in a way which individuals who lack central coherence, (i.e. limited ability to understand context and derive meaning from a large amount of detail; Frith, 1989), may take exaggerated

norms more literally, and not put it into a wider context of the internet and the unrealistic expectations that often go with it.

Social media has enabled young people to have access to interventions that support healthy behaviours and habits (e.g. fitness, meditation, sleep patterns) through phone applications that provide online reinforcement and feedback (Consolvo, Klasnja, McDonald, & Landay, 2012). Online communities are able to offer access to support and services to young people suffering with mental health difficulties, giving young people greater access to many types of intervention or support (Birney, Gunn, Russell, & Ary, 2016; Schickler et al., 2017; Wilansky et al., 2016). Social media has also been used to support parents with parental challenges (Baumel, Pawar, Mathur, Kane, & Correll, 2017).

Furthermore, a recent critical review has highlighted how social media use can provoke social comparison and envy (Verduyn, Ybarra, Résibois, Jonides, & Kross, 2017), which have negative downstream consequences for subjective well-being (Cohen-Charash, 2009; Vecchio, 2000). The key findings from this review concluded;

- *“negative relationships between passively using social network sites and subjective well-being”*
- *“positive relationships between actively using social network sites and subjective well-being, with the former relationship [the negative relationship between active use of social networking sites and subjective well-being] being more robust than the latter [the positive relationship between active use and well-being]” (Verduyn et al., 2017, p.274)*

This implies that when social media is used actively, it can raise levels of well-being (by creating social capital and stimulating feelings of social connectedness); however there is a more robust relationship with the negative effect it can have on well-being.

The research literature indicates wide variation and contradiction of arguments relating to the positive or negative impacts of social media, with many research articles noting the complexity of the association between social media and well-being (Wang, Gaskin, Rost, & Gentile, 2017), which can depend on individual capabilities, culture and psychological functioning (Castellacci & Tveito, 2018) and communication type (Burke & Kraut, 2016). It is important for future research to explore how social media can be operationalised to benefit young people. Therefore, the next step will be to look at life outcomes for the different populations with access to varying levels of social media use.

1.2.17 Life expectations and outcomes

Life outcomes are a particular concern as people with ASC have been found to be disadvantaged in terms of obtaining and sustaining employment (Barnard, Harvey, Potter, & National Autistic Society., 2001). In 2008 it was estimated that only 16% of adults with an ASC diagnosis were in full time employment in the UK, and only 32% were in some kind of work (The National Autistic Society, 2016). However 79% of those not in work and on benefits spoke of wanting to work (HM Government, 2016). This compares to 74.1% of the rest of the population in employment in the UK (Office for National Statistics, 2016).

Employment programmes targeted at individuals with ASC have found particular success for individuals gaining jobs related to technology and computers (D Hedley et al., 2016; Howlin, Alcock, & Burkin, 2005). In some blogs, parents of children with ASC have spoken about how they feel digital communication may aid their children's future employment chances (Microsoft Corporate Blogs, 2015). Employers have also written papers on how to employ people with disabilities (or conditions), highlighting online communication as an effective way of doing this (New Co-Investigator, 2013). There have also been studies with typically developing populations, indicating that *“children who benefit from a greater autonomy of use [of the internet through mobile phones] and a longer online experience [are] reaching the top of the ladder of opportunities”* (Mascheroni & Olafsson, 2016, p. 2).

However, the views of young people with ASC on their life expectations have rarely been systematically collected and recorded. It is unclear from the research if young people with ASC see social networking skills as an open door to employment in the

future compared to previous generations who have not had access to technologically supported communication.

1.3 Research aims/questions and methodology

The focus of this study is on a secondary school aged population, as this is an area of significant interest due to this ages importance in the developmental period, and generally when individuals begin to use social media regularly (Boyd, 2014).

Hopefully, this demographic will be most likely to benefit from the increased understanding the study will bring. This study will aim to explore young people (aged 14-19) with ASC's digital identity and its relationship to their ability to form meaningful relationships, achieve psychological well-being and life outcomes. The study will be in two phases. Research questions 1-4 will be analysed both quantitatively and qualitatively. Research questions 5-6 will only be analysed quantitatively.

The research questions are:

- RQ1: How does use of social media impact the digital identity development for young people with ASC (aged 14-19)?
- RQ2: What is the relationship between digital identity and the ability to form meaningful relationships for young people with ASC (aged 14-19)?
- RQ3: What is the relationship between digital identity and psychological well-being for young people with ASC (aged 14-19)?
- RQ4: Do young people with ASC (aged 14-19) feel social media enables their life outcomes?
- RQ5: What is the relationship between age and digital identity, ability to form meaningful relationships, psychological well-being, and feelings that social media enables life outcomes for young people with ASC (aged 14-19)?
- RQ6: What is the relationship between gender and digital identity, ability to form meaningful relationships, psychological well-being, and feelings that social media enables life outcomes for young people with ASC (aged 14-19)?

Phase one will use demographic information, standardised questionnaires and Likert scales to understand the experiences of young people (aged 14-19) with ASC on their social media use and its relationship to the areas highlighted in RQ 1-6.

Phase two of this study will be a more in depth qualitative exploration of young people (aged 14-19) with ASC and their use of social media as highlighted in RQ 1-4.

Chapter 2: Methodology

2.1 Phase one

2.1.1 Research Paradigm

This study used a positivist approach, seeking empirical evidence in relation to the experiences of young people with ASC when using social media. Knowledge was sought through observable and quantifiable means, including questionnaires and an online focus group.

2.1.2 Research Design

This study used a mixed-methods sequential explanatory design, consisting of two consecutive phases within one study; quantitative followed by qualitative (Creswell & Plano Clark, 2011). This design has strengths that offset the disadvantages of both qualitative and quantitative research and provides a more complete and comprehensive understanding of the research than either approach alone. It also allows the qualitative results to further explain and interpret the findings from the quantitative results.

During phase one, a survey method was used, with the questionnaire being posted on social media groups and fora, trying to find a large sample of young people with ASC who were willing to take part. A paper version of the questionnaire was created and given to schools with ASC participants who agreed to take part. A Pearson's correlation was used to understand if there is a linear relationship between any of the variable measures (e.g. digital identity, friendships, well-being and life outcomes). This could be a positive linear relationship (as one variable rises so does the other) or a negative linear relationship (as one variable increases, the other decreases). Parametric tests and

descriptive statistics were undertaken. Although the statistics suggested that there was some violation of normality, this could be expected within a large sample size. This is due to the normality test being highly powered and therefore able to detect even small and non-important deviations from normality (Pallant, 2010).

A power analysis was undertaken with the PASS program (Hintze, 2004) which is used to estimate sample size or determine the power of a statistical test or confidence interval. It was indicated that 80 participants would be required to detect a small effect ($d=.3$) with 90% power using a Pearson's correlation with an alpha at .15. This means that at least 80 participants will be needed to reject the null hypothesis and accept the alternative hypothesis, providing a correlation of at least $d=.3$ is observed.

2.1.3 Sampling Strategy

Three methods of non-random sampling were used initially. A total of 85 participants were recruited using a mix of handpicked sampling ($n = 56$), snowball sampling, and volunteer sampling (number of participants recruited this way unknown as participants were not asked where they found the questionnaire).

Firstly, volunteer sampling was used. A link was posted across the following social media platforms and participants were encouraged to complete a link to an online survey:

- Facebook (various Facebook groups).
- Twitter
- Reddit fora (Autism, Teen Aspies, Asperger's subreddits)
- Word Press blogging.

Potential participants were asked to provide consent (see appendix 2) and then were invited to complete the questionnaire.

Following this, handpicked sampling was used. The individual bloggers (56) were contacted via email using an online directory of Autism bloggers (An Autism Observer; WordPress). This is a method of purposive sampling, as those selected were individuals in the autism/social media community that are especially knowledgeable and experienced with online communication and social media, due to their interest in blogging (Creswell & Plano Clark, 2011). It was also noted by Bernard (2002) that it is important to select individuals who have the availability and willingness to participate, while having the ability to express their experiences and views articulately, in an expressive and reflective manner. Furthermore, as the blogs of this group were available to view online, it was possible for the researcher to judge that participants had these capabilities.

The participants were encouraged to pass on the information to other people they knew who may be interested. Therefore, an element of snowball sampling (where participants pass on details to other potential participants) was used.

Of the participants recruited from the internet, many were from international websites and fora, therefore this sample is international.

For a further five participants, a method of purposive opportunistic sampling was used. Participants were recruited through schools, who selected appropriate individuals and invited them to take part. Consent was given by parents through a consent sheet (see appendix 3).

2.1.4 Recruitment and inclusion criteria

For the participants that were recruited online, they were asked if they had an ASC diagnosis (and if so when they received the diagnosis), or if they self-diagnosed or identified as an individual with ASC, while using social media.

Four schools were identified as having appropriate students for data collection. A variety of schools were contacted to access a wide range of participants: two mainstream secondary schools, a specialist provision and a mainstream college with an ASC unit. Students were invited to take part in the study providing they had received a diagnosis of ASC (or self-identify) and use social media. Information about how these individuals identified online was explored through responses to questions on the Autistic Digital Identity Scale and the Non-Autistic Digital Identity Scale (see section 2.1.7). The five participants who gave their consent were all from the specialist provision.

2.1.5 Participant details

Overall, there were 85 participants in phase one and six participants in phase two.

Forty-one participants identified as 'female', 36 identified as 'male' and 8 identified as 'other'. Please see Table 1 on page 26 for definitions of who those who identified themselves as 'other'. This definition of 'other' is provided by the American Psychological Association Dictionary of Psychology (2015a) and the Guidelines for Psychological Practice With Transgender and Gender Nonconforming People (American Psychological Association, 2015b). However, whether this definition matched the understanding held by participants who selected this response option is unknown. For more information on gender, see section 1.2.5 on page 23.

2.1.6 Data Information/Collection

During phase one, a survey method to collect data was used. A questionnaire was developed, comprising three standardised measures to assess digital identity, relationship formation, and well-being. Four simple questions on a Likert scale were used to ascertain views about life outcomes.

For the questionnaire in full, please see appendix 4.

The questionnaire was piloted by initially seeking feedback from research supervisors, to check for clarity. Following this, they were shown to Dr Steven Kapp (Research Fellow in Autism and Neurodiversity at the University of Exeter), who provided recommendations, including providing an extra section for participants to provide additional comments, to augment responses to the questions presented and provide supplementary information if relevant. Participants were also invited to provide feedback at the end of the questionnaire. These sections were monitored as the first 20 questionnaire responses were returned, to check for feedback on typographical errors and ensure that questions were clear to participants.

See Table 3 for a full list of participants who completed each questionnaire (some questionnaires were not scored due to missing data).

Table 3: Numbers of participants who completed scales

| Scale | Number of participants |
|--|-------------------------------|
| Participants in total | 85 |
| Autism Digital Identity Scale (ADIS) | 83 |
| Non-Autistic Digital Identity Scale (NADIS) | 83 |
| Friendship Questionnaire (FS) | 79 |
| Moods and Feelings Questionnaire (MFQ) | 82 |
| Life Outcomes: Work | 82 |
| Life Outcomes: Relationships | 82 |

2.1.7 Demographic questions

To begin the online questionnaire, questions about the participant's demographics were asked;

- To which of the following do you most identify? (male, female, other; transgender man, transgender woman, gender binary, gender fluid, etc.)
- What is your age?
- Have you received a formal diagnosis?
 - If so, when was the diagnosis received?
- What type of setting do you live in (rural, village, small town, large town, city)?
- Roughly how long have you used digital media as a means of communication (less than 1 year, 1-2 years, 3-4 years, 5-6 years, 7+ years)?
- Roughly how many hours a day do you spend on social media (Less than 30 minutes, 30 mins–1 hour, 1-2 hours, 3-4 hours, 5+ hours)?

- What methods of digital communication do you use (Facebook, twitter, Instagram, Tumblr, online gaming, forums; e.g. reddit, other)?

It is important to note that in the first question (with regard to gender), the list of suggestions following ‘other’ are only proposals of what the participant may have meant and the definition of ‘other’ was to be chosen by the participant.

2.1.8 The Autistic Digital Identity Scale

The Autistic Digital Identity Scale (ADIS) and Non-Autistic Digital Identity Scale (NADIS) is an adaptation of the Autism Identity Scale (AIS; Jarrett, 2014), which itself was an adaptation of the Deaf Acculturation Scale (DAS; Maxwell-McCaw & Zea, 2011), as there was no measurement for digital identity in autistic adolescents. The DAS was originally used to measure whether an individual feels aligned with deaf community, the hearing community, or both/neither. It was measured across five areas; cultural preference, cultural knowledge, cultural involvement, cultural identification, and language competence (Maxwell-McCaw & Zea, 2011). For the purpose of this study, the ADIS will be used to measure how strongly young people with ASC feel their digital identity is autistic (as oppose to not autistic) and the NADIS will be used to measure how strongly young people with ASC feel their digital identity is non-autistic. There are 32 items within two scales (autism; ADIS and non-autism acculturation; NADIS), with statements given about digital identity. Each item is measured using a Likert scale, where one of the following is selected, strongly agree, agree, neutral, disagree, and strongly disagree.

A Cronbach’s alpha is a measure of internal consistency, for example, how closely related a set of items are in a group. A Cronbach’s alpha was undertaken with all scales

and previous research was referred to, to understand the internal consistency of each measure. It is important to note that due regard is needed about the sample size when calculating a Cronbach's alpha, with some researchers suggesting a sample size of 30 is sufficient, with others suggesting 300 or more is needed (Bonett, 2002).

Previous studies (Maxwell-McCaw & Zea, 2011) have found the DAS to have a good internal reliability, with a Cronbach's alpha score of .91 and .95 for the respective scales. A Cronbach's alpha undertaken on the data used in this study was shown to be .86 and .86 for the respective scales.

Following completion of each group of four questions (see appendix 4) in the ADIS and NADIS, a further question was provided in addition to the questionnaire that said;

- *If you have any further comments on any of these answers, please enter here.*

The following responses were given from this part of the questionnaire;

- Digital identity; 37 responses (from questionnaire), 839 words.

This information was then analysed using a thematic analysis (Braun & Clarke, 2006, 2013), to understand if there were common categories emerging from this data. The computer program NVivo 11 for Windows was used to assist in this analysis.

2.1.9 The Friendship Scale

The Friendship Scale (FS; Baron-Cohen & Wheelwright, 2003) was used to measure perceptions of; enjoying close, empathetic, and supportive friendships; like of and interest in people; enjoying interaction for its own sake; and finding friendships important. The FS was used to understand and measure the participants' ability and interest in forming relationships both online and offline. It contains 35 multiple choice items, with a variety of scoring methods. Each answer is scored (some items are more

heavily weighted than others) and a friendship score between 0 and 135 is generated. In the 2003 study, the average score for males with ASC was 47.1, and for females with ASC it was 47.9. The average score for males with suspected ASC was 42.8, for females with suspected ASC it was 48.8. The average scores for non-autistic males was 51.2, and non-autistic females was 68.3 (Baron-Cohen & Wheelwright, 2003). Previous studies (Hawthorne, 2006) have found the FS to have a good internal reliability with a Cronbach's alpha score of .83. A Cronbach's alpha undertaken on the data used in this study was shown to be .80.

2.1.10 The Moods and Feelings Questionnaire

The Moods and Feelings Questionnaire short-form (MFQ; Angold & Costello, 1987) is used to measure how someone has been feeling recently; for the purpose of this study to measure well-being. There is evidence from prior research for its validity in a population of young people with ASC (Patel, Day, Jones, & Mazefsky, 2017; White, Schry, & Maddox, 2012). It contains 13 multiple questions on a Likert scale. Each answer is given a score of 0, 1 or 2, with 0 being not true, 1 being sometimes, and 2 being true. A total score is made between 0 and 26, and a score of 12 or higher may signify an individual is suffering from depression (and therefore low well-being). It must be noted that there may be an issue in assuming any young person who scores 12 or higher on a short questionnaire has depression, as relatively little information is acquired from the participant. It is also solely relying on self-report and it may be more beneficial to gain views from others around the young person. Similarly, the questionnaire was written in 1987, and the conception of mental health may have changed over the 30 years prior to the original publication. However, as this measure was designed for use children and adults, it is quick to administer, uses simple language

and is a broad view of well-being; it was felt by the researcher and their supervisors that it would be the most appropriate measure to use in the full questionnaire.

Previous studies (Angold, Messer, Pickles, Winder, & Silver, 1995) have found the MFQ to have a good internal reliability with a Cronbach's alpha score of 0.85 with both a typical population (Angold, Messer, Pickles, Winder, & Silver, 1995) and a sample of young people with ASC (Patel et al., 2017). It is important to acknowledge that Patel et al.'s (2017) study had a sample of 25 participants and it has been noted that a higher sample size than 25 may be required to ensure reliability of the Cronbach's alpha score (Bonett, 2002). A Cronbach's alpha undertaken on the data used in this study was shown to be .91.

2.1.11 Life outcomes questions

To measure a young person's views on their life outcomes, a literature search was undertaken to establish if there were any previously used measures that would be appropriate. No such measure was found, so it was decided that four questions with responses provided using a Likert scale would suffice. It was therefore decided that a five-point Likert scale would be used to seek information in relation to two key areas relating to life outcomes; work/school and relationships. Statements were drafted by the researcher and checked by supervisors. It was agreed that two of these items would be reversed to help cross-check item validity. These statements were;

1. Through online communication, I am more likely to find employment
2. Because of online communication, I will be able to make more friends
3. Because of online communication, I am less likely to meet a long-term partner
4. Because of online communication, I am less likely to achieve in school/college

The purpose of this scale was to gain an indication of how young people with ASC feel about their life outcomes; and how strong those feelings are. This scale will also give an indication of which aspects of their life outcomes they feel is most positively linked to online communication.

For questions one and two the responses will be given a score between 0 and 4; with 0 being 'definitely false', 1 is 'somewhat false', 2 is 'neither true nor false', 3 is 'somewhat true' and 4 is 'definitely true'.

For questions three and four (the negatively scored items), the scores given will be; 4 for 'definitely false', 3 for 'somewhat false', 2 for 'neither true nor false', 1 for 'somewhat true' and 0 for 'definitely true'.

Two separate scores will be computed for life outcomes, with one regarding life outcomes in terms of relationships (questions 2 and 3) and another with life outcomes regarding work (questions 1 and 4). The two scores will be between 2 and 10, with a higher score indicating a more positive viewpoint on life outcomes.

2.1.12 Data Analysis

Phase one of this study used a questionnaire design and all information was based on information obtained from the participant. In phase one for RQ1-5, the data was analysed within a correlational design (with a Pearson's correlation) and each variable was checked for normality through histograms, using the SPSS program. Kurtosis and skewness was analysed from the histograms, followed with an exploration of the Q-Q plots.

For RQ6, the data was analysed using a one-way ANOVA was used to explore associations between the three grouped genders; male, female and other and digital

identity, friendships, well-being and life outcomes. This was also completed using the SPSS program.

2.2 Phase two

2.2.1 Research Design

For phase two, the explanatory element of a mixed methods sequential explanatory design was used. This was to add further qualitative information to explain the survey data found in phase one. A forum-based discussion was used to ascertain the views of the participants. Broad questions were provided, and the participants were asked to discuss the questions and respond to each other, while sharing their thoughts.

2.2.2 Participant recruitment/inclusion criteria

After initial quantitative analysis in phase one, phase two began where participants who were involved during phase one were asked at the end of the questionnaire;

“Thank you for your participation. If you are happy to be contacted and be involved in the second part of this study, please enter your email address below.

_____”

This method of purposive sampling was used to create a group which was diverse in terms of demographics (e.g., age, gender, employment/school/college, participation in online research), which should aid finding any phenomenon occurring (Maykut & Morehouse, 1994).

The chosen participants were then contacted by email to see if they were happy to be involved in a forum-based discussion, which was seen to be a focus group style interaction, to ascertain more in-depth views about their opinions on social media, relationship formation, well-being and life outcomes.

Twenty-six of the participants (of the 32 who agreed to take part) who provided their email address were invited to a private online forum (only viewable by those who had been invited via my admin account) powered by google groups. These participants were chosen to create a representative sample in terms of gender as the majority of the participants who opted to take part in phase two were female, therefore an equal balance between 'males' and 'females' was created. Upon joining the group, this message was provided;

Thank you for agreeing to take part in phase two of this study into autism spectrum condition/disorder and social media.

In the following forum I will ask 3 questions in 3 separate threads. Please add your thoughts. Please respond to each other's comments and get a debate going. As the moderator, I may contribute if I feel it will encourage the debate.

I have a £30 Amazon voucher to give away (this can be used on Amazon internationally) – users who contribute to the forum will be put into a draw to win as a prize.

Please try to be as respectful as possible, any offensive or insulting comments will be deleted, and users will be banned. Following the end of the debate, this thread will be deleted, and the full debate will only be viewed by the researchers. Quotes may be used in the final research write-up. The only people invited to view/contribute to this forum have taken part in phase one. At any point you have the right to withdraw and have your comments deleted (and they will not be included in the research).

Otherwise please contribute as much as you can, and I look forward to hearing your thoughts. Any questions please email me on ad564@exeter.ac.uk.

Three threads were created in this forum based around the three key chosen areas; relationships, well-being and life outcomes. The following three statements were posted in the three separate threads;

- *How has being active online affected your ability to form meaningful relationships (online and offline)? Please discuss and feel free to respond to each other.*
- *What effect do you think the emergence of online communication will have on your future outcomes (e.g., employment)? Please discuss and respond to each other.*
- *How has being active online affected your well-being (e.g., your levels of happiness)? Please discuss and respond to each other.*

2.2.3 Data Information/Collection

Of the 32 participants who provided their email address and therefore opted to take part in phase two of this study, of which 26 were invited to the forum-based discussion group. Of those who were invited, six took part, giving 38 responses in the following threads;

- Well-being; 12 posts by 6 authors, 1048 words
- Relationships; 16 posts by 6 authors, 1450 words
- Life outcomes; 10 posts by 5 authors, 849 words

2.2.4 Data Analysis

During phase two, analysis of the forum-based discussion, transcribed responses were analysed using content analysis, a method used to find patterns within a body of text (Cohen, Manion, & Morrison, 2002; Neuendorf, 2016). The computer program NVivo 11 for Windows was used to assist in this analysis.

Initially, contributions to the fora were read and examined for key content. From this a number of categories were derived to organise statements into clusters of similar units of information. This enabled the majority of responses to be coded.

The following steps were taken:

1. Reading of all typed fora contributions in full.
2. Initial organisation into basic categories around the four key areas (relationships, well-being, outcomes, digital identity) in NVivo 11 for Windows.
3. Developing sub-categories relating to the four main categories.
4. Coding the responses in NVivo 11, acknowledging all categories and sub-categories.
5. Repeated examination and refining of each category and sub-category within the data.
6. Reporting of the findings.

2.2.5 Conclusion drawing and verification

For the final step of this analysis, the qualitative data must be analysed and cross-checked to verify the meaning of the data. As described by Miles and Huberman (1994, p.11); *"The meanings emerging from the data have to be tested for their plausibility, their sturdiness, their 'confirmability' - that is, their validity"*.

Validity in this context means that any conclusion that is drawn from the data must be credible, defensible, warranted, and able to withstand alternative explanations (Frechtling & Sharp, 1997). Miles and Huberman (1994) outlined methods of confirming findings that can be used as "safeguards against self-delusion" (p. 265), which were acknowledged during analysis to maximise validity.

Trustworthiness of the qualitative analysis was established through the re-coding of the data independently and the repeated examination and reframing of each category within the data. The researcher engaged in a process of self-reflection with regard to the understanding of the categories during the data analysis phase, to try to minimize potential researcher bias. This was through research supervision, allowing the researcher to address issues relating to subjectivity and providing an opportunity for critical reflection on why the data had been analysed in that way (Mortari, 2015).

To further assure credibility, the data was shown to both research supervisors who commented on the data and checked the coding to try and challenge researcher bias that may have been present. Dependability was ensured as all information was used in its entirety during the analysis phase.

2.2.6 Representativeness of sample:

Due to the volunteer sampling nature of the participant's involvement in this research, it was difficult to ensure a representativeness of the sample. However, it appears that the majority of the participants who were recruited via online fora were active members of the autism community which enabled them to find the questionnaire.

2.2.7 Researcher effects:

There was no involvement at all from the researcher, other than posing the initial question. Due to the online nature of the forum, the participants appeared to use the forum to discuss with each other rather than pose questions to the researcher. On the home page the intentions were made clear for all the informants (e.g. why the forum was being used, information about the researcher, how the data would be used; Miles & Huberman, 1994).

All information was triangulated with other data collection methods (e.g. responses to standardised scales) to ensure that the forum data was not the only way of understanding the experiences of young people with autism in their use of social media.

2.2.8 *Weighing the effects:*

As with all qualitative research, the circumstances of the data collection will have strengthened or weakened the quality of the data (Miles & Huberman, 1994).

The data was collected in an informal setting which was an area of comfort for all the participants as they were all already social media users. Similarly, it was made clear that only the researcher and participants invited to take part had access to the forum, so there was no presence of others.

The responses given on the forum were collected over a short period of time (six days), which means the participants may have only been giving their current view, not their long-term feelings.

Similarly, as it was a forum-based discussion there may have been an element of social desirability, as some participants may have wanted to agree with the statements of the initial posters, rather than be contrary. Participants may have also wanted to give socially desirable responses, as they would have been aware that other members of the ASC community would be reading their responses. Similarly, they may have chosen to contribute in order to receive the financial incentive (the £30 Amazon voucher).

However the joint opinions from a group still hold weight and relevance to the research questions presented. The voices of the individuals will also be acknowledged through two case studies.

2.3 Ethics

All participants were shown a web page (or given an information sheet if filling in manually; see appendix 1) before completing the online questionnaire, where information was provided explaining the purpose of the study, the methods involved, dissemination of the results, contact details, procedures outlined if there is a complaint. The information regarding privacy, confidentiality, right to withdraw, and security of the information given was also provided.

As the study involved individuals with ASC, the vulnerability of this population was considered. The information sheet was clear that participation was voluntary; that every question did not have to be answered; and that participants had the right to withdraw from the study at any point without explanation. This study also focused on recruiting participants at the higher functioning end of ASC, described with average and above average intelligence (Frith, 1989), therefore it was assumed they were competent to give consent, unless there was evidence to the contrary. Communication difficulties were taken into account when wording the information sheets and consent forms. Parental consent was necessary for the younger participants recruited through schools that completed the paper-based questionnaire. With the online questionnaire, participants who were between the ages of 14 and 17 were not allowed to proceed with the questionnaire unless they confirmed they had permission from their parent/guardian. The National Health Service (2018) outlines that children and young people are able to give consent to treatment under the age of 16 as long as they have the intelligence, competence and understanding to fully appreciate what's involved. As the recruitment process was entirely voluntary and participants could not proceed until they had read the

information sheet and agreed to give their (or their parents') consent, there was an assumption that active participation in the survey indicated that consent had been given.

Personal data from the questionnaire and focus group was anonymised, and no identifiable information was processed except for email address for contact regarding phase two – which was given on a voluntary basis. Computer data files were all password protected, and completed questionnaires were stored in a locked area. No personally identifying information was given through the reporting of the results.

Careful consideration was given to the sensitive issues raised in phase two of the study. The questions opening the online discussion forum were carefully worded, as were the probing questions for the digital identity scale on the questionnaire.

Chapter 3: Results. Phase one

3.1 Research Question 1 (quantitative):

How does use of social media impact the digital identity development for young people with ASC (aged 14-19)?

Based on the responses from the ADIS and the NADIS, each participant was grouped into one of the acculturation types outlined in the introduction (see first column of table 4), with ASC being the ‘heritage culture’ and non-ASC identification being ‘receiving culture’ (Schwartz & Zamboanga, 2008);

- *Assimilation: acquires the receiving culture and discards the heritage culture.*
 - *Accepting non-autistic identity and rejecting autistic identity.*
- *Separation: rejects the receiving culture and retains the heritage culture.*
 - *Rejecting non-autistic identity and accepting autistic identity.*
- *Integration: acquires the receiving culture and retains the heritage culture.*
 - *Accepting both non-autistic and autistic identity.*
- *Marginalization: rejects the receiving culture and discards the heritage culture.*
 - *Rejecting both autistic and non-autistic identity.*

If a participant scored over 48 (mid-point) for either the Autism Digital Identity Scale (ADIS) or Non-Autism Digital Identity Scale (NADIS), they were characterised as acquiring the respective culture. If they scored 48 or below, they were characterised as disregarding the culture. The mid-point was chosen as it would have been the score should the participant have responded ‘Neutral/NA’ for every question. Therefore, if the response was above the mid-point, they chose to identify more frequently (and respond with ‘agree’ or ‘strongly agree’) for the respective culture across the questionnaire more than they did for rejecting or feeling neutral about the respective culture (by responding with ‘strongly disagree’, ‘disagree’ or ‘neutral/NA’). For participants to qualify they needed to have fully completed both scales with no missing data. There were 79

participants who completed this questionnaire in full (some participants did not complete all questions and therefore their responses were not accounted for).

Table 4: Digital Identity participant acculturation

| Acculturation type | Definition | Types of scores | Number of participants | Percentage |
|--------------------|--|--|------------------------|------------|
| Assimilation | <i>Acquires the receiving culture and discards the heritage culture.</i> | ADIS: 47 or below NDIS: 48 or above | 23 | 29% |
| Separation | <i>Rejects the receiving culture and retains the heritage culture.</i> | ADIS: 48 or above NDIS: 47 or below | 8 | 10% |
| Integration | <i>Acquires the receiving culture and retains the heritage culture.</i> | ADIS: 48 or above NDIS: 48 or above | 45 | 57% |
| Marginalisation | <i>Rejects the receiving culture and discards the heritage culture.</i> | ADIS: 47 or below NDIS: 47 or below | 3 | 4% |

No significant correlations were found between length of time the participant has been using social media and the ADIS ($r=.060$, $p=.590$) or the NADIS ($r=-.033$, $p=.770$) or daily time spent on social media and the ADIS ($r=.146$, $p=.191$) or the NADIS ($r=-.093$, $p=.408$).

3.2 Research Question 2 (quantitative):

What is the relationship between digital identity and ability to form meaningful relationships for young people with ASC (aged 14-19)?

Table 5 shows the mean scores for the FS, in this research and the original paper, Baron-Cohen and Wheelwright (2003). As the original paper grouped participants by gender, they are demonstrated in this way on table 5. In this research, there were eight participants who identified as 'other', who were not included in this table.

Table 5: Mean scores for the Friendship Scale

| Study | Sample size | Mean male with autism score | Mean female with autism score |
|----------------------------------|-------------------------|--|--|
| de Sausmarez, 2018. | 79 (36 male, 43 female) | 51.29 (<i>SD</i> = 22.3) | 63.48 (<i>SD</i> = 22.31) |
| Baron-Cohen & Wheelwright, 2003. | 68 (51 male, 17 female) | 53.2 (<i>SD</i> = 18.3) | 59.8 (<i>SD</i> = 25.1) |

Table 6 shows the descriptive statistics (scale range, number of participants, mean and standard deviation) for digital identity (ADIS and NADIS) and valuing friendships (FS).

Table 6: Descriptive statistics for digital identity and relationships

| Scale | Scale Range | Number of participants | Mean | Standard deviation |
|--|--------------------|-------------------------------|-------------|---------------------------|
| Autistic Digital Identity Scale; Autistic | 16-80 | 83 | 50.76 | 10.51 |
| Autistic Digital Identity Scale; Non-Autistic | 16-80 | 83 | 56.68 | 10.25 |
| Friendship Scale | 0-140 | 79 | 57.6 | 22.9 |

Figure 2 is a scatter graph demonstrating the scores for ASC digital identity (ADIS) and friendships (FQ). The dots on each scatter graph represent their scores for the two scales, for example in this scale the score for the ADIS is represented along the x axis labelled ADIS and the score for the FQ is represented along the y axis labelled FQ.

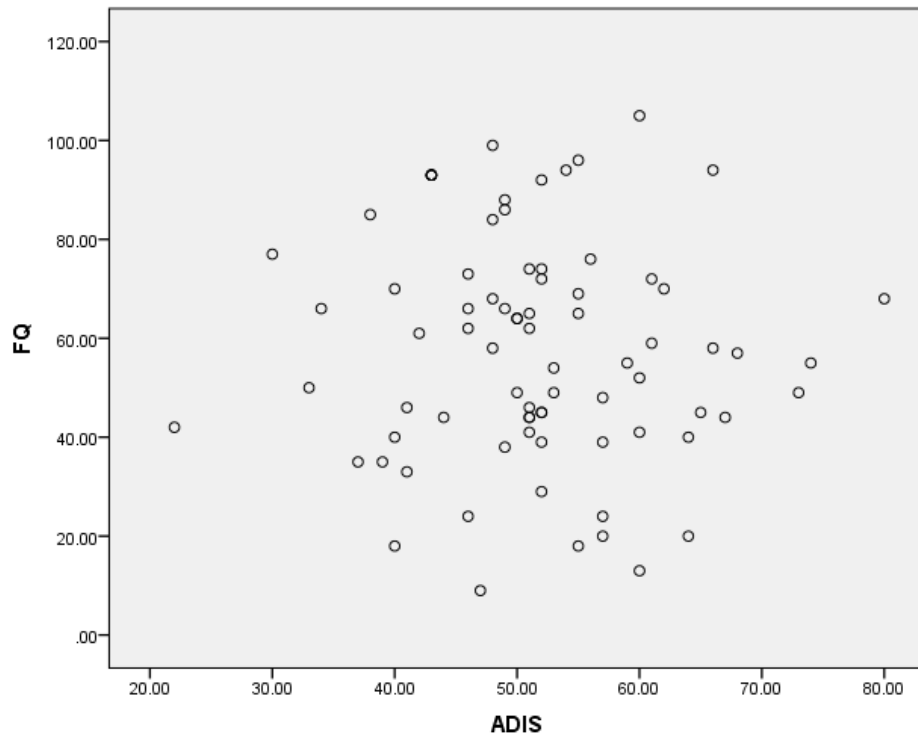


Figure 2: Scatter graph of Autism Digital Identity Scale (ADIS) and Friendships Questionnaire (FQ)

Figure 3 shows a scatter graph, demonstrating the scores for non-ASC digital identity (NADIS) and friendships (FQ).

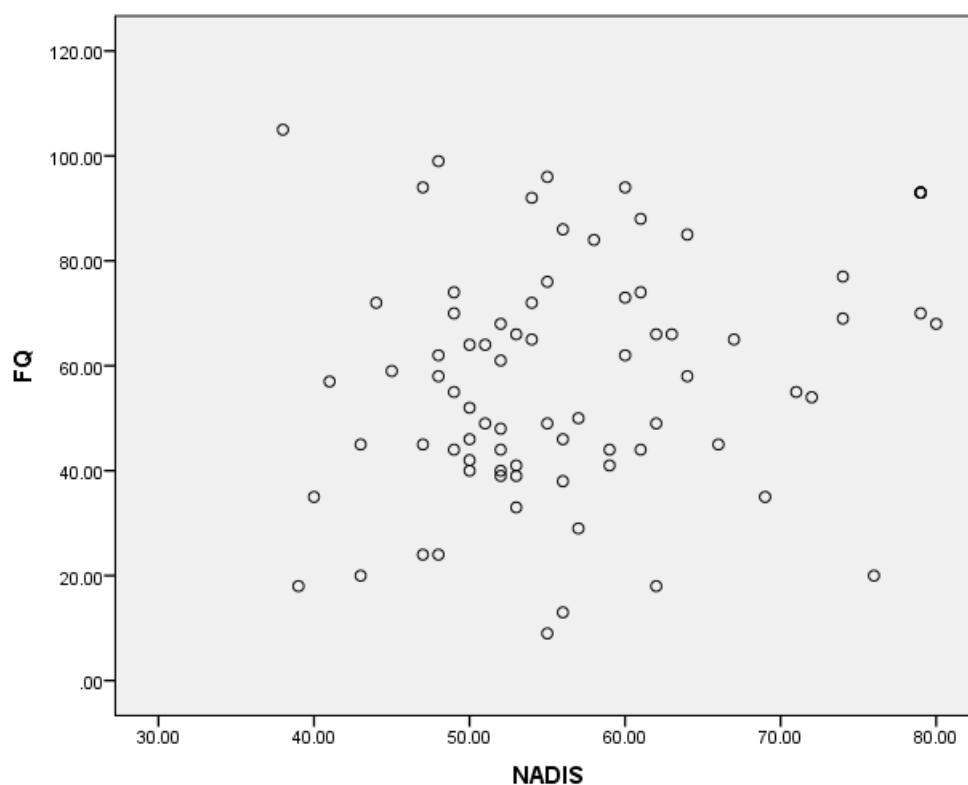


Figure 3: Scatter graph of Non-Autistic Digital Identity Scale; NADIS) and Friendships Questionnaire (FQ)

3.2.1 The relationship between digital identity and valuing friendships

A one-tailed Pearson's correlation was used to explore the relationship between autistic digital identity and friendships, as measured by the ADIS and NADIS (autistic and non-autistic) and the Friendship Questionnaire. No significant correlation was found between identifying as ASC within online communities and valuing friendships (see table below; $r = 0.047$, $p = .683$). However, a significantly weak positive correlation was found between identifying as non-autistic online and valuing friendships ($r = 0.251$, $p =$

.027). This suggests an association between participants who identify as non-autistic online and those that are more likely to enjoy relationships and find them meaningful.

Table 7: Correlations for Digital Identity and Friendship

| | Pearson's correlation | Sig. (one-tailed) |
|---|-----------------------|-------------------|
| Autism Digital Identity and friendships | $r = -.047$ | $p = .683$ |
| Non-Autism Digital Identity and friendships | $r = .251$ | $p = .027$ |

3.3 Research Question 3 (quantitative):

What is the relationship between digital identity and psychological well-being for young people with ASC (aged 14-19)?

Table 8 shows the number of participants who scored over 12 (which may indicate the presence of depression), and how many participants scored below 12 (which does not indicate the presence of depression).

Table 8: Participants MFQ scores over and under 12 (above and below indication of depression)

| Score | Number of participants | Percentage |
|-------------------------------|------------------------|------------|
| Participants scoring over 12 | 45 | 54% |
| Participants scoring under 12 | 39 | 46% |

Table 9 shows the descriptive statistics (scale range, number of participants, mean and standard deviation) for digital identity (ADIS and NADIS) and well-being (MFQ).

Table 9: Descriptive statistics for digital identity and well-being

| Scale | Scale Range | Number of participants | Mean | Standard deviation |
|---|--------------------|-------------------------------|-------------|---------------------------|
| Autistic Digital Identity Scale; Autistic | 16-80 | 83 | 50.76 | 10.51 |
| Autistic Digital Identity Scale; Non-Autistic | 16-80 | 83 | 56.68 | 10.25 |
| Mood and Feelings Questionnaire | 0-24 | 82 | 12.41 | 6.96 |

3.3.1 The relationship between digital identity and well-being

A one-tailed Pearson's correlation was used to explore the relationship between autistic digital identity and well-being, as measured by the ADIS and NADIS (autistic and non-autistic) and the Mood and Feelings Questionnaire (MFQ). No correlation was found between identifying as autistic online and well-being ($r = .124, p = .275$). Similarly, no correlation was found between identifying as autistic online and well-being ($r = -.182, p = .112$).

Table 10: Correlations for digital identity and well-being

| | Pearson's correlation | Sig. (one-tailed) |
|---|-----------------------|-------------------|
| Autistic digital identity and well-being | $r = .124$ | $p = .275$ |
| Non-Autistic digital identity and well-being | $r = -.182$ | $p = .112$ |

Figure 4 is a scatter graph demonstrating the scores for ASC digital identity (ADIS) and well-being (MFQ).

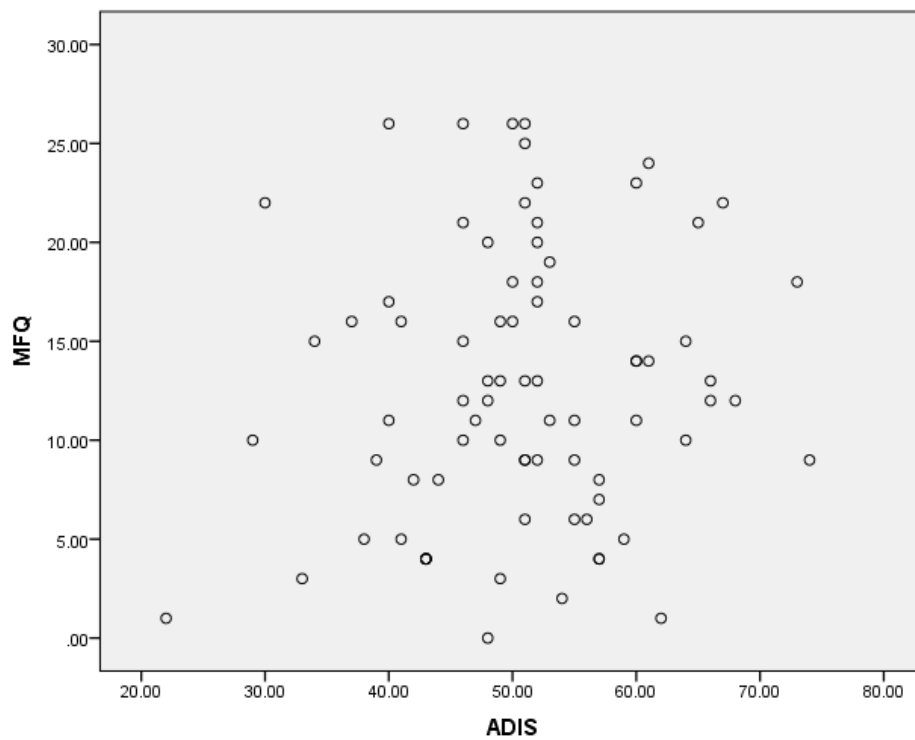


Figure 4: Scatter graph of Autism Identity (Autistic; ADIS) and well-being (MFQ)

Figure 5 is a scatter graph demonstrating the scores for non-ASC digital identity (NADIS) and well-being (MFQ).

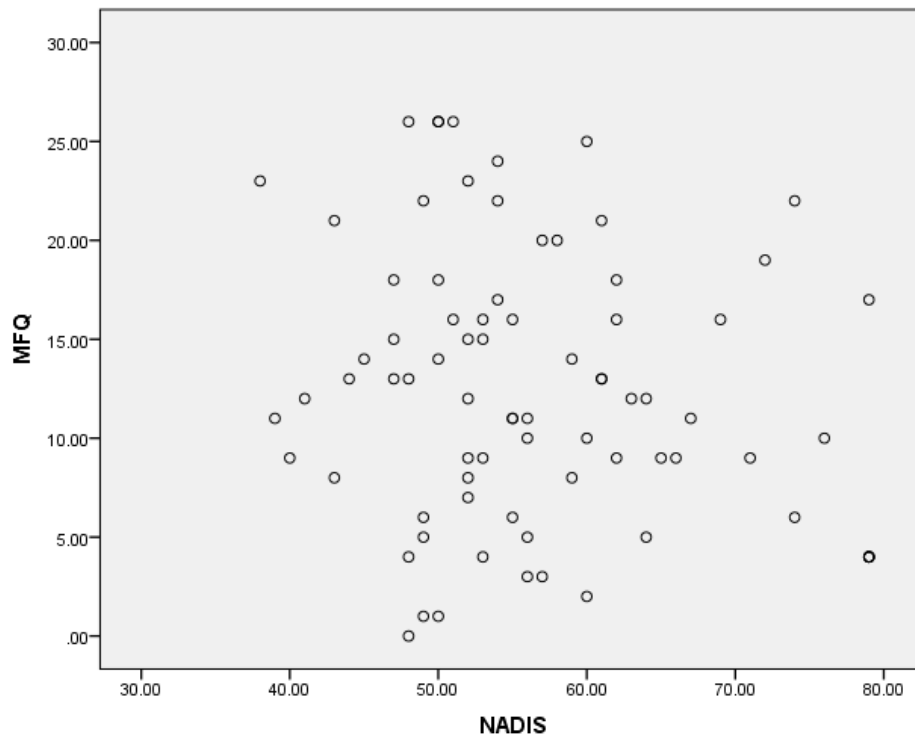


Figure 5: Scatter graph of Autistic Digital Identity (Non-autistic; NADI) and well-being (MFQ)

3.4 Research Question 4 (quantitative):

Do young people with ASC (aged 14-19) feel social media affects their life outcomes?

Table 11 shows the descriptive statistics (scale range, number of participants, mean and standard deviation) for digital identity (ADIS and NADIS) and views on life outcomes (LOw and LOr).

Table 11: Descriptive statistics for digital identity and life outcomes

| Scale | Number of participants | Scale Range | Mean | Standard deviation |
|---|------------------------|-------------|-------|--------------------|
| Autistic Digital Identity Scale; Autistic | 83 | 16-80 | 50.76 | 10.51 |
| Autistic Digital Identity Scale; Non-Autistic | 83 | 16-80 | 56.68 | 10.25 |
| Life Outcomes; Work | 82 | 2-10 | 5.28 | 1.70 |
| Life Outcomes; Relationships | 82 | 2-10 | 5.20 | 1.76 |

3.4.1 The relationship between digital identity and views on life outcomes

A one-tailed Pearson's correlation was used to explore the relationship between autistic digital identity and view of life outcomes, as measured by the ADIS and NADIS (autistic and non-autistic) and views on life outcomes. No correlation was found between identifying as autistic online and believing online communication will have a positive effect on work outcomes ($r = .148, p = .191$). However, a weak significant

correlation was found between autism digital identity and believing the internet will have a positive impact on relationship outcomes ($r = .368, p = .001$).

Weak significant negative correlations were found between non-autistic digital identity (identifying as non-autistic online) and believing the internet will improve both work ($r = -.382, p = .001$) and relationship outcomes ($r = -.365, p = .001$). This shows there is a weak negative relationship between identifying with a non-autistic population and beliefs about making friends, having relationships, gaining employment and getting better grades due to the internet.

Table 12: Correlations for digital identity and life outcomes

| | Pearson's correlation | Sig. (one-tailed) |
|---|-----------------------|-------------------|
| Autistic digital identity and work outcomes | .148 | .191 |
| Autistic digital identity and relationship outcomes | .368 | .001 |
| Non-Autistic digital identity and work outcomes | -.382 | .001 |
| Non-Autistic digital identity and relationship outcomes | -.365 | .001 |

Figure 6 is a scatter graph demonstrating the scores for ASC digital identity (ADIS) and life outcomes regarding work (LOW).

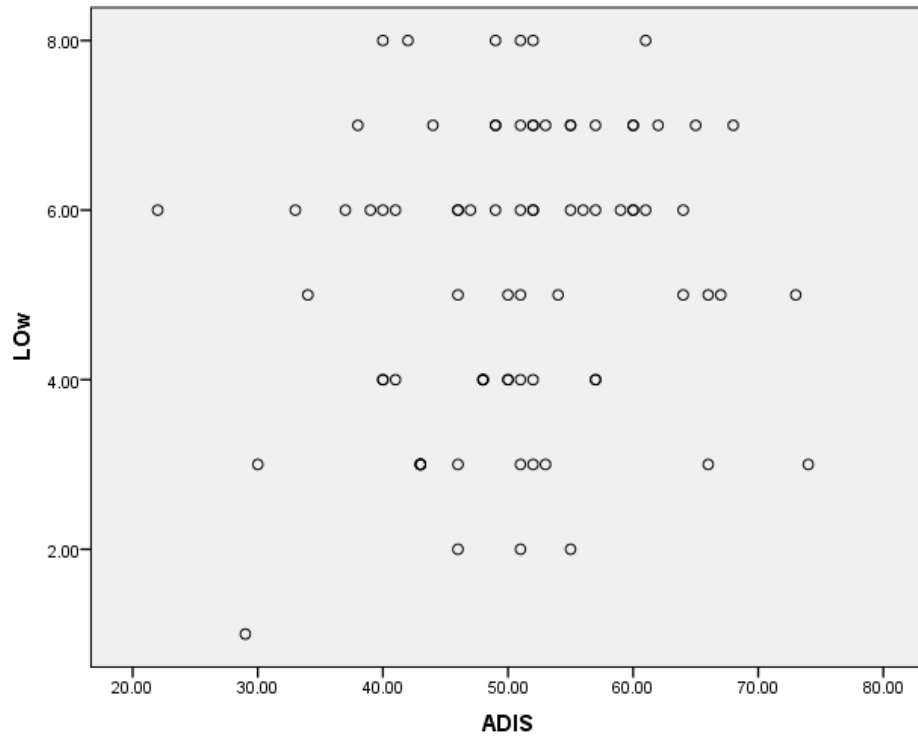


Figure 6: Scatter graph of Autistic Digital Identity (Autistic; ADIS) and Life Outcomes (Work)

Figure 7 is a scatter graph demonstrating the scores for ASC digital identity (ADIS) and life outcomes regarding relationships (LOR).

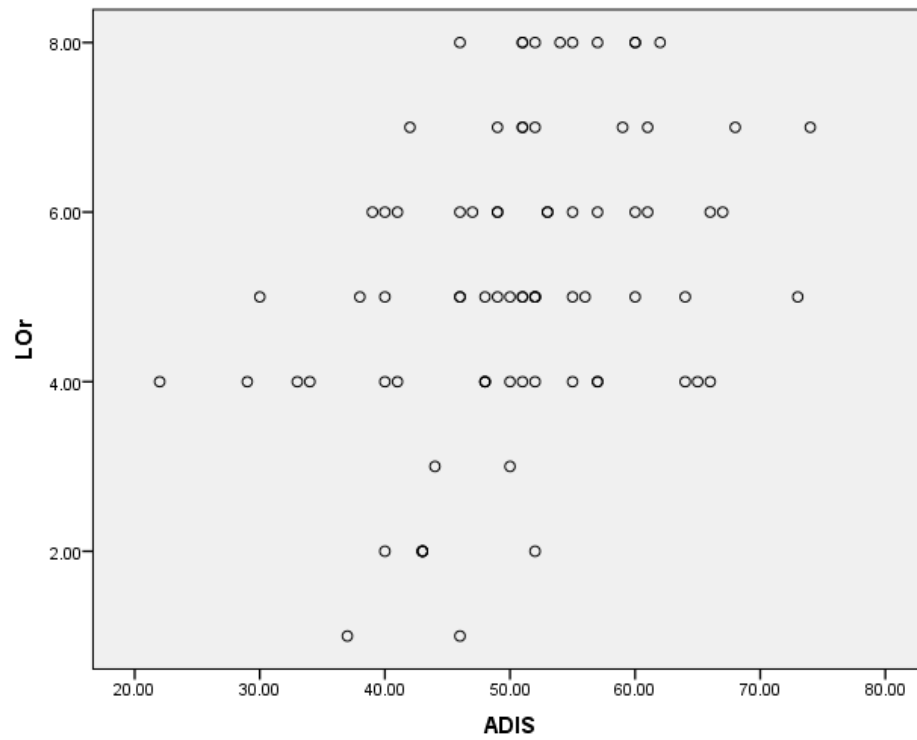


Figure 7: Scatter graph of Autistic Digital Identity (Autistic; ADIS) and Life Outcomes (Relationships)

Figure 8 is a scatter graph demonstrating the scores for non-ASC digital identity (NADIS) and life outcomes regarding work (LOW).

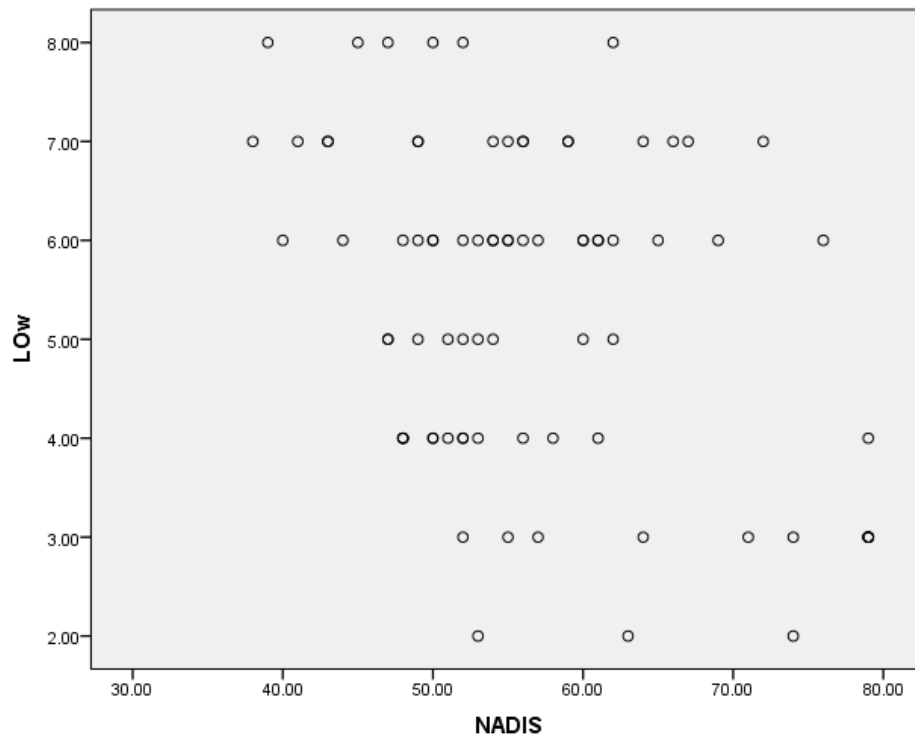


Figure 8: Scatter graph of Autistic Digital Identity (Non-autistic; NADIS) and Life Outcomes (Work)

Figure 9 is a scatter graph demonstrating the scores for non-ASC digital identity (NADIS) and life outcomes regarding work (LOr).

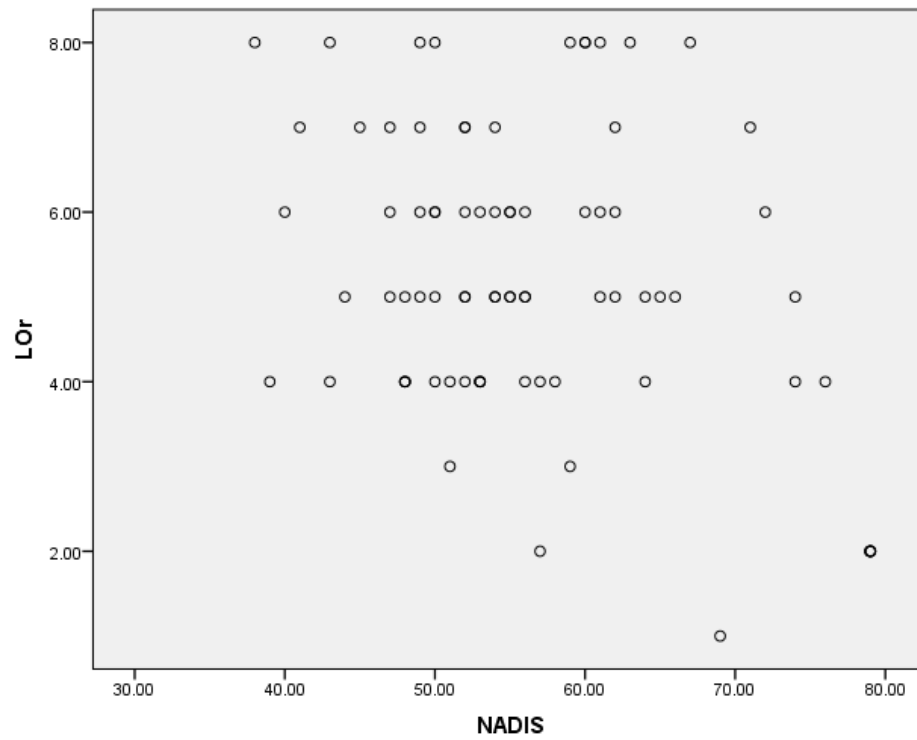


Figure 9: Scatter graph of Autistic Digital Identity (Non-autistic; NADIS) and Life Outcomes (Relationships)

3.5 Research Question 5

What is the relationship between age and digital identity, ability to form meaningful relationships, psychological well-being, and feelings social media enables life outcomes for young people with ASC (aged 14-19)?

Table 13 shows the descriptive statistics (scale range, number of participants, mean and standard deviation) for age, digital identity (ADIS and NADIS), valuing friendships (FS), well-being (MFQ) and views on life outcomes (LOw and LOr).

Table 13: Descriptive statistics for age, digital identity, friendships, well-being and life outcomes

| Scale | Scale Range | Number of participants | Mean | Standard deviation |
|---|--------------------|-------------------------------|-------------|---------------------------|
| Age | 14-19 | 85 | 16.89 | 1.68 |
| Autistic Digital Identity Scale; Autistic | 16-80 | 83 | 50.76 | 10.51 |
| Autistic Digital Identity Scale; Non-Autistic | 16-80 | 83 | 56.68 | 10.25 |
| Friendship Scale | 0-140 | 79 | 57.6 | 22.9 |
| Mood and Feelings Questionnaire | 0-24 | 82 | 12.41 | 6.96 |
| Life Outcomes; Work | 2-10 | 82 | 5.28 | 1.70 |
| Life Outcomes; Relationships | 2-10 | 82 | 5.20 | 1.76 |

3.5.1 The relationship between age and digital identity, ability to form meaningful relationships, psychological well-being, and feelings of social media enabling life outcomes

A one-tailed Pearson's correlation was used to explore the relationship between age and digital identity, friendships, well-being and life outcomes (as measured by the ADIS, NADIS, FS, MFQ and life outcomes questions on a Likert scale) and the results are shown in Table 14. No correlation was found between age and autistic digital identity ($r = .08, p = .486$) and non-autistic digital identity ($r = -.03, p = .758$). No correlation was found between age and friendships ($r = .09, p = .436$). No correlation was found between age and well-being ($r = .03, p = .761$). No correlation was found between age and views on life outcomes with regards to relationships ($r = -.07, p = .530$) or college/job opportunities ($r = -.08, p = .501$).

Table 14: Correlations for age and digital identity, valuing friendships, well-being and views on life outcomes

| | Pearson's correlation | Sig. (one-tailed) |
|---------------------------------------|-----------------------|-------------------|
| Age and Autistic digital identity | .08 | .486 |
| Age and Non-Autistic digital identity | -.03 | .758 |
| Age and friendships | .09 | .436 |
| Age and well-being | .03 | .761 |
| Age and life outcomes (relationships) | .07 | .530 |
| Age and life outcomes (work/college) | -.08 | .501 |

3.6 Research Question 6

What is the relationship between gender and digital identity, ability to form meaningful relationships, psychological well-being, and feelings social media enables life outcomes for young people with ASC (aged 14-19)?

Table 15 shows the descriptive statistics (scale range, number of participants, mean and standard deviation) for gender, digital identity (ADIS and NADIS), valuing friendships (FS), well-being (MFQ) and views on life outcomes (LOw and LOr).

Table 15: Descriptive statistics for gender, digital identity, friendships, well-being and life outcomes

| Scale | Scale Range | Number of participants | Mean | Standard deviation |
|---|--------------------|-------------------------------|-------------|---------------------------|
| Gender | N/A | 85 | N/A | N/A |
| Autistic Digital Identity Scale; Autistic | 16-80 | 83 | 50.76 | 10.51 |
| Autistic Digital Identity Scale; Non-Autistic | 16-80 | 83 | 56.68 | 10.25 |
| Friendship Scale | 0-140 | 79 | 57.6 | 22.9 |
| Mood and Feelings Questionnaire | 0-24 | 82 | 12.41 | 6.96 |
| Life Outcomes; Work | 2-10 | 82 | 5.28 | 1.70 |
| Life Outcomes; Relationships | 2-10 | 82 | 5.20 | 1.76 |

Not every participant completed all items in all questionnaires, therefore there was some missing data. This is the reason for the different number of participants for each scale.

3.6.1 The relationship between gender and digital identity, ability to form meaningful relationships, psychological well-being, and feelings of social media enabling life outcomes

A one-way analysis of variance (ANOVA) was used to understand the difference between the three grouped genders (male, female, other) and ability to form meaningful relationships, psychological well-being, and feelings social media enables life outcomes.

There were no reported statistical differences between gender groups; male, female and other and Autistic Digital Identity (as measured by ADIS) as determined by a one-way ANOVA ($F(2,81) = 2.79, p = .069$). There similarly were no reported statistical differences between gender groups; male, female and other and Non-Autistic Digital Identity (as measured by NADIS) as determined by a one-way ANOVA ($F(2,80) = .628, p = .54$).

There were no reported statistical differences between gender groups; male, female and other and friendships (as measured by FS) as determined by a one-way ANOVA ($F(2,78) = 2.7, p = .071$).

There were no reported statistical differences between gender groups; male, female and other and well-being (as measured by MFQ) as determined by a one-way ANOVA ($F(2,81) = 1.36, p = .262$).

There were no reported statistical differences between gender groups; male, female and other and life outcomes (relationships; as measured by LOr) as determined by a One-

way ANOVA ($F(2,81) = .306, p = .737$). There were also no reported statistical differences between gender groups; male, female and other and life outcomes (work/college; as measured by LOw) as determined by a one-way ANOVA ($F(2,81) = .725, p = .488$).

Table 16: One-way ANOVA for gender (male, female, other) and autistic/non-autistic identity, friendships, well-being and life outcomes

| Source | | Sum of Squares | Df | Mean Square | F | Sig. |
|--------|----------------|----------------|----|-------------|------|------|
| ADIS | Between Groups | 589.64 | 2 | 294.82 | 2.79 | .068 |
| | Within Groups | 8349.46 | 79 | 105.69 | | |
| | Total | 8939.12 | 81 | | | |
| | | | | | | |
| NADIS | Between Groups | 133.10 | 2 | 66.56 | .63 | .536 |
| | Within Groups | 8266.90 | 78 | 105.99 | | |
| | Total | 8400.00 | 80 | | | |
| | | | | | | |
| FS | Between Groups | 2690.12 | 2 | 1345.06 | 2.73 | .071 |
| | Within Groups | 37389.24 | 76 | 491.96 | | |
| | Total | 40079.37 | 78 | | | |
| | | | | | | |
| MFQ | Between Groups | 130.67 | 2 | 65.34 | 1.36 | .262 |
| | Within Groups | 3789.23 | 79 | 47.97 | | |
| | Total | 3919.90 | 81 | | | |
| | | | | | | |
| LOw | Between Groups | 1.80 | 2 | .901 | .306 | .737 |
| | Within Groups | 232.75 | 79 | 2.95 | | |
| | Total | 234.55 | 81 | | | |
| | | | | | | |
| LOr | Between Groups | 4.52 | 2 | 2.26 | .73 | .488 |
| | Within Groups | 246.36 | 79 | 3.12 | | |
| | Total | 250.88 | 81 | | | |
| | | | | | | |

3.7 Results; qualitative digital identity additional responses from questionnaire

A thematic analysis was undertaken from the additional responses given in the online questionnaire, where the participants were given an option to provide further comments following completion of the ADIS or NADIS (see appendix 4 for full questionnaire and 5 for thematic analysis of all interview data). For more information see section 2.1.7.

This analysis was completed in a full document and separated into the following key areas separated into eight key areas. The key areas reported were;

- Choosing/Disclosing the ASC identity
- Difficulties with ASC identity
- Choosing not to use ASC identity online
- Advantages online
- Learning about friendships
- Meeting new people
- Stress in friendships
- Social support

Table 17: Views given to surplus digital identity scale

| Sub-category | Summary | Illustrative data |
|---|--|--|
| Choosing/Disclosing the ASC identity | Two participants spoke of choosing to associate themselves with ASC and feeling the need to tell others. | <i>“I would rather associate myself with Aspergers”</i> <i>“sometimes I feel the need to tell people”</i> |
| ASC identity – negative view | One participant spoke of not wishing ASC on anyone. | <i>“It is important to understand that I wouldn't wish autism on anyone”</i> |
| Choosing not to use ASC identity online | Five participants spoke of choosing not to use the ASC identity online. Some spoke of it being because they feel ASC is less visible online, others preferred not to, and some saw it as protection. | <i>“I like to separate the part of me that identifies as autistic and save that for autism communities rather than it always being a part of me whilst online”</i> <i>“I feel comfortable online with people who aren't autistic, as we</i> |

| | | |
|----------------------------|---|---|
| | | <i>normally have other things in common”</i> |
| | | <i>“I don't always want to discuss autism as sometimes it frustrates or exhausts me that I am different, and I also just don't see autism as my entire identity”</i> |
| Advantages | One person spoke about the positive impact online communication has had on their social lives. | <i>“Being online makes the social aspect easier.”</i> |
| Learning about friendships | Two people spoke of the importance of learning about friendships. One spoke about learning more about ASC through autism communities, the other spoke of the importance of learning social skills from non-autistic people. | <i>“I get the majority of my information from autism communities or from the National Autistic Society who I follow on Facebook and Twitter”</i> <i>“It is also important to associate with non-autistic people to pick up on their behaviour and emotional reactions under certain situations so that we can gain a better understanding of normal behaviour”</i> |
| Meeting new people | Six people spoke about wanting to meet new people, or how online communication has enabled them to meet more people than they would have otherwise. There were frequent references to hearing views and experiences and learning to improve communication skills. The importance of meeting both those with and without ASC was also noted. | <i>“I think that socializing with people who don't have autism is just as important as with people who have it is”</i> <i>“It's easier to connect with others who have autism online than in person”</i> <i>“I like to see other people's views and experiences as lots of people experience autism differently”</i> <i>“Being surrounded by people who don't have autism, has pushed me to improve my communication skills”</i> |

| | | |
|-----------------------|---|--|
| Stress in friendships | One participant spoke of finding relationships with other people with autism difficult. | <i>“the last question i dont like being with other people its so unconformable being around other with the same thing because you don not know how they will act or even if they get upset with something you both disagree with.”</i> |
| Social support | One participant spoke of giving and receiving social support. | <i>“When I do engage myself in autistic communities, I do like to discuss issues that I and others have, as well as looking up things that I might be struggling with.”</i> |

Chapter 3. Results: Phase two

The following section details the findings from phase two of the study. The final section will be discussing two chosen case studies who have been given pseudonyms; Philippa and Alexis. For the fully coded data, see appendix 6.

3.8 *Qualitative analysis*

A systematic qualitative data analysis was undertaken (Huberman & Miles, 1983; Miles, Huberman, & Saldaña, 2014), a method of displaying data to make sense of a large data set, which may otherwise be spread over many pages. The responses on the online questionnaire were organised into four key areas of interests; digital identity, friendships, well-being and life outcomes (see appendix 5 and 6 for thematic analysis of all interview data).

3.8.1 *Data Display*

Six participants were involved in the forum-based discussion. Each participant's involvement ranged from 2 to 13 posts (see table below). Each participant's name has been removed and they have been identified as Participant 1 (P1), Participant 2 (P2), etc.

The quotes detailing a positive impact were highlighted in **bold**, with the quotes detailing a negative impact in *italics*, with the neutral quotes in underlined.

The findings are displayed on table 18. The participants' scores in phase one are provided, along with the mean and range scores for each scale. Categories and sub-categories are shown in table 19.

Table 18: Systematic Qualitative Analysis

| Participant | Mean | Range | 1 | 2 | 3 | 4 | 5 | 6 |
|--|-------|-------|----|----|----|----|----|----|
| Phase one | | | | | | | | |
| Autism Digital Identity Scale score | 50.76 | 16-80 | 73 | 74 | 53 | 51 | 44 | 52 |
| Non-Autism Digital Identity Scale score | 56.68 | 16-80 | 62 | 71 | 54 | 60 | 59 | 61 |
| Friendship Scale score | 63.51 | 79 | 61 | 72 | 79 | 63 | 46 | 86 |
| Moods Feelings Questionnaire score | 12.65 | 26 | 18 | 9 | 24 | 25 | 8 | 21 |
| Life Outcomes-Work | 5.30 | 6 | 5 | 3 | 6 | 6 | 7 | 6 |
| Life Outcomes-Relationships | 5.17 | 7 | 5 | 7 | 6 | 8 | 3 | 8 |
| Phase two | | | | | | | | |
| Number of posts | 6 | 11 | 13 | 8 | 7 | 3 | 3 | 2 |
| DI Choosing/Disclosing the ASC identity | | | X | | | | | |
| <u>No ASC identity online</u> | | | X | | | | | |
| F Advantages online | | | X | X | X | | | X |
| Lower stress in online communication | | | X | X | X | | X | X |
| Learning about friendships | | | | X | | | | |
| Meeting new people | | | X | X | X | | | X |
| More friends online | | | | | X | X | X | X |
| <i>Relationship difficulties</i> | | | X | X | | | | |
| WB Higher well-being | | | X | | X | | X | X |
| <i>Lower well-being</i> | | | | X | | | | |
| <i>Difficulties with online relationships</i> | | | | X | | | | |
| Social support | | | X | X | X | X | | X |
| LO Confidence | | | | | X | | | |
| Employment opportunities | | | X | X | | X | | |

Table 19: Key for categories and sub-categories

| Key | Category | Sub-category |
|-----|------------------|--|
| DI | Digital Identity | 1. Choosing/Disclosing the ASC identity 2. <i>Difficulties with ASC identity</i> 3. <u>Choosing not to use ASC identity online</u> |
| F | Friendship | 1. Advantages online 2. Lower stress in online communication 3. Learning about friendships 4. Meeting new people 5. More friends online 6. <i>Relationship difficulties</i> 7. <i>Stress in friendships</i> |
| WB | Well-Being | 1. Higher well-being 2. <i>Lower well-being</i> 3. <i>Difficulties with online relationships</i> 4. Social support |
| LO | Life Outcomes | 1. Confidence 2. Employment opportunities |

X = Present for that participant

Table 20: Data display in cross-case analysis

| Participants views on social media | | | |
|------------------------------------|--|--|--|
| Category | Sub-category | Most commonly occurring across all participants | Why |
| Digital Identity | <ul style="list-style-type: none"> Choosing/ Disclosing the ASC identity Choosing not to use ASC identity online | <ul style="list-style-type: none"> Choosing/ Disclosing the ASC identity Choosing not to use ASC identity online | One participant appears to identify with both ASC and non-ASC communities online. |
| Friendships | <ul style="list-style-type: none"> Advantages online Lower stress in online communication Learning about friendships Meeting new people More friends online Relationship difficulties Stress in friendships | <ul style="list-style-type: none"> Eye contact/time pressures Advantages online Meeting new people More friends online | Five of the participants spoke of enjoying communication through social media due to removal of eye contact and time pressures. This had a knock-on effect on their ability to meet people and make friends. |
| Well-being | <ul style="list-style-type: none"> Higher well-being Lower well-being Difficulties with online relationships Social support | <ul style="list-style-type: none"> Social support Higher well-being | Five participants spoke of the social support they have found through others online. On the forum they were sharing strategies used to help their own difficulties. |
| Life Outcomes | <ul style="list-style-type: none"> Confidence Employment opportunities | <ul style="list-style-type: none"> Employment opportunities | Two participants suggested that they believe that they are more likely to find employment in the future due to online communication reducing the need for face-to-face interactions in the workplace. |

3.8.5 Summary of qualitative data

Following the table provided above, each of the sub-categories have been summarised, with illustrative data providing examples of quotes from the participants.

Table 21: Summary of category 1 qualitative data: views on digital identity

| Sub-category | Summary | Illustrative data |
|--------------------------------------|--|--|
| Choosing/disclosing the ASC identity | One participant spoke of still wanting to choose the ASC identity when online. | <i>“the online world is worth taking advantage of if it works for you. Why should I force myself to socialise at neurotypical standards if that creates high anxiety?”</i> |
| No ASC identity online | One participant spoke of feeling that their social difficulties are less obvious online. | <i>“I feel like social awkwardness isn't so obvious online”</i> |

Table 22: Summary of category 2 qualitative data: views on friendships

| Sub-category | Summary | Illustrative data |
|--------------------------------------|---|---|
| Advantages | Four of the participants emphasised the positive impact online communication has had on their social lives a total of 11 times. Many reasons were given including; less time-related pressures, access to others who are similar and increased social confidence. | <p><i>“I find it a lot easier to communicate through social media instead of face to face. I can start up conversations or join in conversations really easily which I wouldn't have the confidence to do in person. “</i></p> <p><i>“[the internet] has provided me with a form of social communication which I could not have gotten if I didn't have it”</i></p> <p><i>“Online has been my main method of social interaction, and therefore my activity online has been vital for my social well-being and happiness. Even though I may have a lower threshold of minimum social interaction than the average person, some social interaction is still highly necessary for any person.”</i></p> |
| Lower stress in online communication | Fifteen examples were given from five participants across all text around finding social interaction easier online, due to lower stress in friendships, for example the removal of pressures such as giving eye contact and an instant response. This was the highest occurring sub-category across the text. | <p><i>“Being online means that I can talk to people when I have the energy to, and they won't necessarily mind if I need to step away for an hour or a day or so, whereas a person in real life may look at me weirdly if I were to walk away in the middle of a conversation.”</i></p> <p><i>“I feel like I don't have to be ashamed of my social awkwardness and I can embrace it”</i></p> <p><i>“I can take time to give across the point I want to give and edit it if something I write doesn't make much sense until I'm happy</i></p> |

| | | |
|----------------------------|--|--|
| | | <p><i>with it. There aren't so many rules--you can't make eye contact, or stand incorrectly, or do many things wrong online, but in real life, it's a completely different minefield and everyone else seems to have been given the map showing how to avoid them, meaning you're the one who constantly messes up and lands yourself in trouble!"</i></p> <p><i>"on social media you don't have to worry about things like making eye contact or thinking of an answer immediately, which can be really difficult"</i></p> <p><i>"I can say with 100% confidence that if it wasn't for online communication then I wouldn't have anywhere near as many opportunities presented to me"</i></p> |
| Learning about friendships | Two people spoke of feeling that they have been able to learn more about ASC and forming friendships through discussing with others or following relevant pages on the internet. | <p><i>"I wouldn't know half the coping mechanisms I do if it wasn't for recommendations from people online, especially regarding problems I have that I wouldn't talk about in real life"</i></p> |
| Meeting new people | Four participants gave seven examples of how online communication has enabled them to meet more people than they would have otherwise. There were frequent references to hearing views and experiences and learning to improve communication skills. The importance of meeting both those with and without ASC was also noted. | <p><i>"Being online has made me a lot happier, as it has given me a platform to meet and connect with people who I wouldn't have had the opportunity to meet otherwise"</i></p> <p><i>"Through my blogging, I have also seen different perspectives in the world, and I began to understand the world of people who aren't like me. One of my best friends, not autistic, was</i></p> |

| | | |
|---------------------------|---|--|
| | | <p><i>formed through an online friendship.”</i></p> <p><i>“It wasn't until I got really involved in the online community that I realised just how different people can be. It's definitely helped me emphasise with larger, more diverse groups of people.”</i></p> |
| More friends online | <p>Four participants gave eight references throughout the text to individuals feeling that they have more friends due to online communication. This was related to making new friendships and maintaining prior friendships.</p> | <p><i>“Without the Internet I doubt any of my friends would still be engaging with me in any way at all, and in fact, there are friends I have lost contact with due to their minimal presence online”</i></p> <p><i>“Being active online was the best choice for me when trying to form relationships with Asperger's.”</i></p> <p><i>“my current closest friends went to my secondary school but we didn't really know each other that well but then started talking on Facebook a year ago and now hang out all the time”</i></p> |
| Relationship difficulties | <p>Some relationship difficulties were noted by two participants. One participant spoke of developing a dependence on online communication which has made it difficult to communicate in day to day life. Both participants of difficulties while speaking to others in different time zones.</p> | <p><i>“although I have formed many online communications and friendships, I have lost almost all my offline relationships and I don't really leave the house anymore.”</i></p> <p><i>“I have made so many online friends, i can't meet up with any of them and often they are from different time zones so my sleeping patterns get messed up trying to chat to them.”</i></p> <p><i>“time zones can definitely be a problem! I've experienced difficulty with this in the past”</i></p> |

Table 23: Summary of category 3 qualitative data: views on well-being

| Sub-category | Summary | Illustrative data |
|--|---|---|
| Higher well-being | Four of the participants gave eight references regarding how internet use has had a positive impact on their well-being. This was often related to the opportunities of friendships online communication has provided. | <p><i>“I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it.”</i></p> <p><i>“Online has been my main method of social interaction, and therefore my activity online has been vital for my social well-being and happiness”</i></p> <p><i>“[Online communication] made me feel like I belonged as part of a community, something all humans arguably need, whereas I had felt like I stood out like a sore thumb my whole life. I finally had a whole heap of people who could relate to my experiences, and I didn't even need to get out of bed. It was like discovering a whole other world full of acceptance, and I've loved it since.”</i></p> |
| Lower well-being | One participant spoke twice of the negative impact social media has had on their lives. This related to cyber bullying and social isolation. | <i>“I was unhappy and [missed] out whole periods of my life.”</i> |
| Difficulties with online relationships | One participant gave five references to the negative impacts social media use has had on their well-being. Many of these were related to problems with relationships (see relationship difficulties section in category 2). | <p><i>“in the long run I have frequently linked being online to my times of unhappiness.”</i></p> <p><i>“Recently, I got a puppy, and the training and care she needs has drawn me away from the internet and as a result, I have been happier and have even found a partner.”</i></p> |

Social support

One of the highest occurring sub-categories was the social support with five participants and nine references given to online relationships provide which in term increase levels of well-being.

“[The internet] has also made me happier by improving my confidence, as when I am online I tend to be more outgoing, as I find it a lot easier to communicate through social media instead of face to face.”

“made me feel like I belonged as part of a community, something all humans arguably need, whereas I had felt like I stood out like a sore thumb my whole life. I finally had a whole heap of people who could relate to my experiences”

“I felt like there were people online who understood my quirky and unusual ways and felt the same. it was nice to feel like I fitted in somewhere”

“I know for a fact I wouldn't be here if it wasn't for the times my friends went out of their way to talk me out of things”

Table 24: Summary of Category 4 qualitative data: views on outcomes

| Sub-category | Summary | Illustrative data |
|--------------------------|---|--|
| Confidence | One participant spoke of how online communication has increased their confidence in seeking employment. | <i>“I think online communication helps me with future employment as otherwise I would not have any prospects, because I am not confident enough to go places and ask for jobs. sometimes, opportunities come my way online.”</i> |
| Employment opportunities | Three participants gave four references to online communication leading to an increased feeling of success in employment. | <p><i>“When I have gone to interviews before, I have completely panicked and not known what to say. With my last employer, they allowed me to take a online interview instead in which I passed with flying colors.”</i></p> <p><i>“My nervousness around communication, and social anxiety disorder in general, make it impossible for me to call people, so I can say with 100% confidence that if it wasn't for online communication then I wouldn't have anywhere near as many opportunities presented to me.”</i></p> <p><i>“i think it will help future employment for me, as id prefer to work behind a screen or with technology than with people face-to-face. i am also much more productive and helpful with online work than paper-work so i would be able to do my job more efficiently.”</i></p> |

Chapter 3. Results: Case Study

The final section will discuss two chosen case studies, who have been given the following pseudonyms: Philippa and Alexis. These participants were chosen based on their high levels of contribution to phase two and insightful responses given. These case studies were constructed from information obtained from participants that made extensive contributions in the online forum in phase 2. As their email address was viewable by the researcher (as an administrator of the forum), their scores in phase 1 could be found and reported alongside their phase 2 responses.

3.9 Case study 1 - Philippa

Philippa is an 18-year-old female with a formal diagnosis of Autism. She received a diagnosis at age 17 and lives in a town. She is a blogger and an avid user of social media, using Facebook, Twitter, Instagram and Snapchat for up to five or more hours a day. She has used social media for 5-6 years.

From the questionnaire, Philippa received the following scores;

Table 25: Philippa's scores

| Measure | Philippa's Score | Mean from study population | Mean if previously standardised | Range |
|--------------------------------------|-------------------------|-----------------------------------|---|--------------|
| Autism digital Identity | 73 | 50.76 (SD=10.51) | N/A | 16-80 |
| Non-autism digital identity | 62 | 56.68 (SD=10.25) | N/A | 16-80 |
| The Friendship Scale | 49 | 57.6 (SD=22.9) | 59.8 (SD = 25.1) – for females with ASC | 0-140 |
| The Moods and Feelings Questionnaire | 18 | 12.41 (SD=6.96) | N/A | 0-24 |
| Life Outcomes – relationships | 5 | 5.28 (SD=1.7) | N/A | 2-10 |
| Life Outcomes – Employment | 5 | 5.20 (SD=1.76) | N/A | 2-10 |

3.9.1 Philippa's Digital Identity

Philippa appears to identify more as someone with ASC online than she does as someone without ASC, as her score for ASC digital identity is two standard deviations above the mean. However, her score for non-ASC digital identity was at around the average point for this sample of young people.

3.9.2 Philippa's friendships

Philippa's score for the friendship scale was 49, which is within the average range for a young female of her age with an ASC diagnosis.

In phase two, Philippa spoke about enjoying the closed nature of her online relationships particularly as if she gets in disagreements with others, she feels they are less likely to share the information surrounding the disagreement (see second comment); *“I find it difficult to trust people in real life because I see friendship groups break down incredibly easily”*

“It's rare that someone will dish out everything they can online if you fall out, and even if they do, it's not like others will fall out with you, because there's less chance of them finding the information.”

Philippa spoke about feeling that when online, she finds it easier to find topics of conversation:

“[social media is] a great way of catching up informally, especially as people usually talk about what they're doing online so you have a topic of interest to talk about when you do chat”

She also spoke of being able to form friendships with people who have similar interests to her:

“Although I no longer talk to them regularly, a group of girls I met on a writing website at the age of twelve got me through of some of my most difficult years as a young teenager. We were there to support each other, and there wasn't the same pressure when it came to keeping certain things to yourself. I still check up on them every now and again and it's great to see how we've all grown as time has gone on.”

Phillipa also emphasised the positive impact she believes social media to have had on her ability to form friendships;

“I’ve definitely learnt to trust people, and how to build healthy relationships with people, through the experiences I’ve gained online.”

3.9.3 Philippa’s’ well-being

Philippa had a score of 18 on the Moods and Feelings Questionnaire, implying that her well-being is at the low-end of average for this population. She noted that she feels that the diagnosis has had a significantly positive effect on her since she recently received her autism diagnosis:

“I didn’t receive my diagnosis until I was [17], so seeing other people online being positive about their condition definitely helped me to accept that it wasn’t a bad thing or something I needed to be ashamed of.”

She reports feeling that the online autism community has made her feel supported. This would support her high score for autism digital identity:

“It also made me feel like I belonged as part of a community, something all humans arguably need”

“It was like discovering a whole other world full of acceptance”

Philippa noted that she had seen a psychiatric nurse who endorsed her use of the online world, with her reporting he said:

“the online world is worth taking advantage of if it works for you”

3.9.4 Philippa's views on her life outcomes

Philippa felt it was 'somewhat true' that use of social media will improve her chances of finding employment. However, she feels it will have no effect on her success at school/college.

Furthermore, she noted that it is 'definitely true' that she has made more friends due to social media, but felt it was 'somewhat true' that social media may make it more difficult for her to find a romantic relationship.

During phase two, Philippa noted that she feels that there have been big advancements for young people like her in terms being able to access opportunities for employment due to the change in the nature of recruitment. However, it is important to note that Philippa is only 18 years old so may not have much employment experience, so her knowledge about employers may be limited;

"A lot of employers are getting on board with the online world now, with advertisements for job positions and application forms now taking place on the internet, where you can send your CV and information over to an individual in a company without having to speak to them verbally. This allows those of us who struggle with spontaneous speech, or speech in general, to have a chance at job opportunities that may not have been an option years ago."

Philippa reported feeling that due to her being able to communicate online and via email without experiencing social anxiety has made it much easier to share her thoughts, particularly with employers. She stated;

"I can say with 100% confidence that if it wasn't for online communication then I wouldn't have anywhere near as many opportunities presented to me"

Philippa also spoke of how the distinctive features of her ASC may be an asset in the workplace, but she is concerned that it is difficult for her to communicate those special strengths to employers using the paper based application process.

“I can present my unique abilities and help a job in ways they might not have imagined by using things I've learned, even though what shows on paper may not present that”

3.9.5 Case study summary

Philippa appears to be communicating that she feels online communication has had a positive impact on her in many aspects of her life, including; friendships, well-being and life outcomes.

Philippa identifies strongly as an individual with ASC and appears average in terms of her desire to form relationships and the impact of this on her well-being (for a female with ASC). She emphasised that the internet has had a positive impact on her relationships, which in turn has had a positive impact on her well-being, as she has been able to engage and communicate with others with ASC.

3.10 Case study 2- Alexis

Alexis is a 14-year-old female with a formal diagnosis of Autism. She received a diagnosis at age 10-13 and lives in a small town/village. She is a blogger and an avid user of social media, using Tumblr, Twitter, Instagram, YouTube and online gaming for up to 5 or more hours a day. She has used social media for 1-2 years.

From the questionnaire, Alexis received the following scores;

Table 26: Alexis's scores

| Measure | Alexis's Score | Mean from study population | Mean if previously standardised | Range |
|--------------------------------------|----------------|----------------------------|---|-------|
| Autism digital Identity | 74 | 50.76 (SD=10.51) | N/A | 16-80 |
| Non-autism digital identity | 71 | 56.68 (SD=10.25) | N/A | 16-80 |
| The Friendship Scale | 55 | 57.6 (SD=22.9) | 59.8 (SD = 25.1) – for females with ASC | 0-140 |
| The Moods and Feelings Questionnaire | 9 | 12.41 (SD=6.96) | N/A | 0-24 |
| Life Outcomes – relationships | 7 | 5.28 (SD=1.7) | N/A | 2-10 |
| Life Outcomes - Employment | 3 | 5.20 (SD=1.76) | N/A | 2-10 |

3.10.1 Alexis's Digital Identity

Alexis appears to identify equally as someone with autism online as she does as someone without autism. Both her scores are within two standard deviations above the

mean. This implies she has an integrated identity, identifying strongly online with the autistic and non-autistic online communities.

3.10.2 Alexis's friendships

Alexis's score for the friendship scale was 55, which is average for a young female with an ASC diagnosis. This implies that Alexis has a need for close, meaningful relationships, similar to what would be typically expected from a young female with ASC.

In phase two, Alexis spoke about how she no longer has relationships other than those online:

"I have lost almost all my offline relationships and I don't really leave the house anymore"

This suggests that although Alexis appears to enjoys close, empathetic and supportive friendships (as she gained an average score in the FS), she has struggled to make them in the offline world and has only been able to have friendships in the online world.

However, she noted that she wants to make more offline friends and is actively trying to expand her friendships:

"I have made a point of this year to try and make some offline friends and although I have not made very many, I frequently meet up with the few friends I have made."

Alexis noted that she often does not leave the house and does not have many offline friendships, but frequently meets up with the few friends she has. It is unclear why, however it may be that these friends visit her in her house, or her view of 'frequently' meeting up may be defined as infrequent by others (e.g. once every 2 months).

However, without an additional source of information it is difficult to corroborate this information.

She spoke of the knock-on effect that social media use has had on her sleep patterns, due to many of her friends being in different time zones. However, she has explored ways of tackling her sleep difficulties online, such as autonomous sensory meridian response (ASMR) which is visual or auditory stimuli (which can be viewed on online platforms such as YouTube). Many individuals feel ASMR leads to body sensations that can enable relaxation and sleep. Some research has suggested that it is a reliable and physiologically-rooted experience that may have therapeutic benefits for mental and physical health (Poerio, Blakey, Hostler, & Veltri, 2018):

“I have ... suffered with sleeping problems in the past and I found that asmr [autonomous sensory meridian response] really helped me”

3.10.3 Alexis's well-being

Alexis had a score of nine on the Moods and Feelings Questionnaire, implying that her levels of well-being are at a good level.

Alexis reports her online activity having a significant impact on this:

“Being online, has really helped me make new friends and find environments that I can thrive in”

She spoke of social media being a place where she can express herself:

“being able to have a place to express myself has really helped me and I would recommend it to other people definitely. Blogging and other social platforms can be a great place to start.”

However, she noted that balance of her life has been very important, and she has linked times of heavy internet use with times of unhappiness:

“I got addicted and spent my whole life inside.”

She noted there have been times where she has been the victim of cyber-bullying, which she found very difficult:

“I was cyber bullied as a child and as a result I lost all my confidence. For a large period of my life, I didn't talk to anyone and lost contact with all my friends. I sought help from a councilor who I still see and she helped me so much with my self confidence and I have grown as a person.”

3.10.4 Alexis's views on her life outcomes

Furthermore, she noted that it is ‘definitely true’ that she has made more friends due to social media, but felt it was ‘somewhat false’ that social media may make it more difficult for her to find a relationship. This may be because as noted, she feels social media has expanded her social circles.

Alexis responded that it was ‘somewhat true’ that use of social media will improve her chances of finding employment, while indicating that it is ‘definitely true’ that she is less likely to achieve well in school or college due to social media. This was not expanded on any further, but could be due to her feeling that she has more flexibility with regards to employment, for example, during the online fora, Alexis noted that she feels that she is more likely to be able to find a job due to being able to communicate online:

“I also have issues going places and talking to people so being able to use online communications can really help with applying to jobs and getting my CV out there.”

She also spoke about when she has had interviews in the past, she has found them difficult. However, she has been able to use online communication, and this has meant she has ‘thrived’:

“When I have gone to interviews before, I have completely panicked and not known what to say. With my last employer, they allowed me to take a online interview instead in which I passed with flying colors.”

Although Alexis is 14 years old, it is important to note that participants were drawn from an international sample, therefore Alexis may have been a resident in a country where young people work from a younger age. However, this could also raise questions about trustworthiness of data, as Alexis may have been seeking to provide a response that she feels is socially desirable.

3.10.5 Case study summary

Alexis was able to communicate a mixed picture of the positive and negative impact online communication has had on her. While she was able to feel that it has improved her chances of making friends and gaining employment, she noted that the internet has somewhat contributed to her becoming isolated from the offline world. She also noted the difficulties associated with cyber bullying.

Chapter 4: Discussion

The discussion will begin with an examination of the research questions in the light of the results obtained and methods used. The findings will then be interpreted, acknowledging alternative explanations, methodological weaknesses and explaining unexpected results. Following this, there will be consideration of the implications for the knowledge base in the area, potential future research and the impact this may have on future educational psychology (EP) practice.

4.1 RQ1: How does use of social media impact the digital identity development for young people with ASC (aged 14-19)?

A discussion of the qualitative and quantitative findings are shown in table 27. This is to demonstrate the findings from both phases alongside each other.

Table 27: Discussion of results relating to RQ1

| RQ1: | |
|---|--|
| Quantitative discussion | Qualitative discussion findings |
| <p>Berry, Trimble, and Olmedo (1986) outlined four different types of acculturation to an identity of a minority group. Acculturation involves maintaining their cultural customs and having relationships with others from their minority group (Schwartz & Zamboanga, 2008);</p> <ul style="list-style-type: none"> • 57%, have both ASC and non-ASC digital identity (integration). Retaining the heritage identity has shown to be a protective mechanism, raising levels of personal and collective self-esteem (Cooper, Smith, & Russell, 2017; Jarrett, 2014). This is significantly higher than previous studies (33%; Jarrett, 2014). • 29% have non-ASC digital identity (assimilation). Other studies involving young people with ASC have found assimilated identity is related to lower self-esteem (Jarrett, 2014). This could be because when online, many of the difficulties a young person with autism may experience with regards to their social communication (e.g. eye contact, time related pressures) are removed, therefore they may have felt it was not necessary for them to develop an autistic identity online. • 10%, experience ASC digital identity, (separation). • 4% experience no digital identity, (marginalization). | <ul style="list-style-type: none"> • The most commonly occurring sub-category was the desire the participants have to meet new people who share a similar identity to them, with them outlining how online communication has enabled them to do this. Another participant felt meeting other people with ASC online has enabled them to see how ASC can be viewed from the perspective of others. However other participants noted the importance of interacting with both people with and without ASC. • Another commonly occurring sub-category was speaking of how the participants do not always feel that they must identify as an individual with ASC online. No participants appeared to totally reject their autistic identity when online, but some noted that it is not always relevant to their online activity. Similarly, one participant noted that they feel well connected with those without ASC. |

Interpretation:

Just over half of the participants in this study (57%) appeared to integrate their identities and identify as both non-autistic and autistic. Jarrett (2014) originally proposed the four types of acculturation discussed in Chapter 1, derived from a study that recruited participants through a school selection procedure, and reporting a lower incidence of integrated identity (33%). This study's sample was recruited through volunteers over the internet, so it can be postulated that participants who use online communication may be more likely to form integrated identities. In phase two, all the participants who chose to contribute to the online fora appeared to show preference for both identities, from their phase one questionnaire responses. However, the four types of acculturation explored in the quantitative discussion were not addressed directly.

One participant in phase two did note that they find their difference “*frustrating*” and “*exhausting*” and for this reason, do not always choose to disclose online. One participant noted that they did not see autism as their “*entire*” identity, which implies an integrated identity. This may be similar to those with Down Syndrome, as it has been hypothesised that social media supported individuals in accepting Down Syndrome as part of their identity, whilst denying the social stigma that comes with a condition, allowing them to build an identity that is different (Benford, 2008), or as a place to “*construct and present multiple selves: a self that is similar to those with Down syndrome and a self which is also different*” (p. 349, Seale, 2001). This multiple identity approach may help those with ASC explore the online world without feeling they need to feel ‘different’, while retaining the protective aspects a label and community belonging can bring (Cooper et al., 2017).

It may be that use of online communication does not only encourage adoption of an ASC identity online, but involvement with the online community in general (both autistic and non-autistic). Similarly, there may be issues with correlation/causation, as it may be that those who wish to be involved in a community and develop an identity may seek out opportunities to communicate with others in a way that works and is lower stress for them, which in the modern day may be online communication for those with ASC (due to the reported lower time pressures and face-to-face social cues).

Many of the participants were bloggers and therefore engaged in positive forms of online communication which could result in them becoming more involved in the community, particularly as social media use has shown to increase levels of civic participation (Livingstone et al., 2005; White, 2016).

It is noted by Brownlow and O'Dell, (2006) in their final conclusions; *"We propose that the Internet is a useful tool in enabling individuals with autism to share their experiences and perceptions of the label 'autism' and have these perceptions and experiences recognized within a professionally dominated discourse of autism."* (p. 320). These young people with ASC may have sought the opportunity to be involved in this research as an opportunity to merge their experiences and perceptions, and the views represented within the professionally dominated discourse of autism research. Similar, many of the volunteers in this study may have been aware of the neurodiversity movement, which has been instrumental in *"celebrating autism as an inseparable aspect of identity"* (Kapp et al., 2013), rather than something that needs to be 'cured' (Bagatell, 2007). As it is felt by many that the role of neurodiversity has not fully been recognised by medical professionals or advocates in the field (Cascio, 2012), being part of a research project that directly seeks the views of those within the online community

could be seen as an opportunity to communicate and merge the feelings of the community into the academic field of professionals. Language used in phase two such as ‘neurotypical’ would also imply that this is the case. Many advocates of this movement have been able to become engaged and enthusiastic about issues for the ASC community, through the learning they have been able to do online (Kapp et al., 2013). This movement coupled with increased opportunities for interaction with non-autistic people is likely to have enabled an ‘integrated’ identity.

The benefits and risks of the development of online identities for individuals with ASC

The findings from this study appear to suggest that the majority (57%) of the participants have developed both autistic and non-autistic identities online. Social media has been shown to impact directly on expression of identity and therefore on how identity is performed and reinforced (Greenhow & Robelia, 2009). For example, when engaging with others who have ASC (e.g. on an ASC advocacy forum), an individual may be more likely to also identify as having ASC. However when they are engaging with typically developing peers, they may not reveal ASC – this pattern of identification as ASC or non-ASC will be reinforced by the responses from both these groups. Therefore, the way digital identity is developing for these young people is important in understanding the experiences of this population, as social media has been shown to allow young people to create an identity and image of how they see themselves and how they want others to see them (Williams & Merten, 2008). Similarly it has been described as a ‘safe’ place, where individuals can network with other people from the ASC community (Dekker, 1999).

The research base has shown that identity can work as a protective mechanism, raising levels of personal and collective self-esteem (Cooper et al., 2017). Similarly frequent users of social networking have also been shown to exhibit greater social trust, higher levels of civic participation (Choi & Shin, 2016; M. Skoric et al., 2015; Valenzuela et al., 2009), and social bonding (Ahn, 2012; Burke et al., 2010), all of which are protective factors against low levels of mental health (Bishop-Fitzpatrick et al., 2017). Although no direct relationship was found between autistic or non-autistic identity, if online communication is facilitating healthy identity development, it should also have a positive impact on all these areas and should be encouraged.

In terms of identity development through meeting new people, encouraging social connectedness for young people with ASC is important (Baumeister & Leary, 1995; Rueger et al., 2016). Many interventions have focused on training social skills in young people with ASC and have found positive results in a number of related areas such as well-being (Laugeson, Frankel, Mogil, & Dillon, 2009; Ozonoff & Miller, 1995; Rumney & Macmahon, 2016; Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007).

In this fast-changing technological landscape, professionals must retain an understanding of how to support young people in a feasible way, as for many, digital media and online communication is a daily occurrence (Kuo et al., 2014). There is emerging research that has utilised digital media and online communication to support young people with ASC in developing their social skills to positive results (Gwynette et al., 2017; Gwynette, Sidhu, & Ceranoglu, 2018; Parsons & Mitchell, 2002).

Young people who experience social communicational difficulties may not have had access to a community of young people who experience similar difficulties as them. Similarly they may not be aware or fully understand the debates around neurodiversity

and difference/deficit (Kapp et al., 2013), which has the potential to be empowering to their identity development if they are more able to form integrated identities. Therefore, professionals working with this population must begin to understand the importance of identity development in the adolescent years (Crocetti, 2017; Meeus, 1996) and how this is impacted by online identity.

While there is a noted lack of understanding from some professionals, there is an online movement and community that will support development of both non-autistic and autistic identities, which should be utilised, providing it is practised safely and in moderation. Professionals must now seek ways to support young people in this area and continue to develop, extend and evaluate social skills programs for online use, as have been used to positive results in both the online and offline world (Laugeson et al., 2009; Ozonoff & Miller, 1995; Rumney & Macmahon, 2016; Tse et al., 2007).

Special interests

Special interests occur highly within the ASC population, as do high levels of social media use (Shane-Simpson et al., 2016). Grove et al. (2018) found a positive link between motivation to engage with special interests in moderation and subjective well-being. Other positive correlations were found relating to satisfaction across specific life domains including social contact and leisure.

However a link was found between high intensity special interests and low levels of subjective well-being (Grove et al., 2018). There have been similar findings regarding over-use of the internet (Block, 2008; Lu et al., 2017; Pugh, 2017; Schimmenti et al., 2017).

This study did not look into special interests for young people with ASC; however both special interests and internet use will have a significant impact on the identity

development of a young person. Therefore, with both special interests and internet use, they should be encouraged for young people with ASC, but in moderation where it does not restrict them from being involved in other aspects of day-to-day life, to enable healthy identity development.

Internet addiction

Some research has suggested that internet use can lead to social isolation, loneliness and lower levels of well-being (Bahrainian, Alizadeh, Raeisoon, Gorji, & Khazaei, 2014; Kraut et al., 1998; Sharifpoor, Javad Khademi, & Mohammadzadeh, 2017). Many of these studies have found these larger negative traits when social media is over-used and restricts young people from being involved in other aspects of day-to-day life. This must be understood within the context of ensuring the internet is used in moderation and a young person does not become addicted to social media use. Some participants suggested that they had become addicted and had negative experiences with social media, therefore they are likely to be suffering from internet addiction and therefore would be expected to have many other difficulties, including low levels of well-being.

4.2 RQ2: What is the relationship between digital identity and the ability to form meaningful relationships for young people with ASC (aged 14-19)?

A discussion of the qualitative and quantitative findings are shown in table 28. This is to demonstrate the findings from both phases alongside each other.

Table 28: Discussion of results relating to RQ2

| RQ2: | |
|--|---|
| Quantitative discussion | Qualitative discussion findings |
| <ul style="list-style-type: none"> • There were higher mean scores for the Friendship Scale responses in comparison to the mean scores initially outlined when the FS was devised (Baron-Cohen & Wheelwright, 2003). This could not be tested for significant difference due to not having access to the original data, however the participants in this study did appear to be showing a stronger desire for close and personal relationships than would be expected from an offline ASC population. • Correlational analysis showed a significant, weak correlation between the Non-Autistic Digital Identity Scale and the FS. This implies that participants who identify as non-autistic online (and therefore show a higher score on the NADIS) are more likely to value closeness in relationships (and therefore show a higher score on the FS) and vice versa. • Correlational analysis found no relationship between the Autistic Digital Identity Scale (ADIS) and the FS. This implies that if a participant identifies as autistic online (and therefore shows a higher score on the ADIS), it will not make a difference to their desire for close and personal relationships (and will not impact on their FS score) and vice versa. | <ul style="list-style-type: none"> • It was reported that an advantage of social media is meeting new people and finding those with similar interests who they can share experiences with who they would otherwise have not been able to meet or have contact with. One participant emphasised that they can 'connect' with other people through online communication. Another participant clarified that they have been able to meet people with many different perspectives, including those who do not have autism. • Another frequently occurring sub-category was around online communication alleviating time and eye contact pressures. One participant noted that in online communication it is socially acceptable to take time out when communication becomes too stressful. • Two participants clarified the difficulties that can come with use of social media. One participant outlined how the internet has had a negative impact on their ability to function within day-to-day life despite having been able to form new friendships online. Two other participants noted that they have made friends who live abroad which has had an impact on their sleeping patterns. |

Interpretation:

It is hypothesised that the higher Friendship Scale mean scores obtained by participants in this study (compared to the original study; Baron-Cohen & Wheelwright, 2003) could

be due to this method of volunteer sampling, where those already using social media (and therefore seeking out relationships via the internet) were demonstrating an elevated need for close, personal relationships i.e. those who use the internet are more likely to show an interest in friendships due to the increased opportunities for interaction online. In phase two, participants spoke of the internet being a place where they could ‘connect’ with others, which could be explained through a research base that explores online communications ability to create ‘hyper personal communication’ (Carpenter, Green, & Laflam, 2018), which is particularly notable in a paper named ‘I’ve Never Clicked this Much with Anyone in My Life’ (Henderson & Gilding, 2004). A recent study clarified how different types of social media use have differing effects on friendships (e.g. private or public posts), with private messaging appearing to lead to greater closeness of friendships (Carpenter et al., 2018). This is particularly important considering Mendelson et al. (2016) noted that children with ASC had significantly lower sociometric status (the degree to which someone is liked or disliked by their peers) and significantly fewer social connections, less frequent interactions with friends and fewer reciprocal friendships than typically developing peers. These participants reported having higher levels of social support over the internet, and the research has shown friendships are a determining factor for young people with ASC’s levels of well-being and self-worth (Kingery et al., 2011; Mendelson et al., 2016).

The correlation between the NADIS and FS could be explained through understanding of ‘deep structure reciprocity’ (see figure 1).

It is noted by Mendelson et al., (2016) that ‘affective sharing’ is a part of a leading model of friendships and is the area that young people with ASC struggle with, despite wanting to have close relationships. Affective sharing is described by Mendelson et al.

(2016) as follows: “...when a child develops the ability to understand subtle social cues, then moderate their own facial expression, body posture, vocal intonation, verbal statements, and gestures to respond. It is this process that lead to deep structure” (p. 3).

If developing friendships online removes the need for face-to-face ‘affective sharing’, then people with ASC still appear to be able to experience ‘affective sharing’ through more remote, online communication. This may lead to the facets of ‘deep structure’ (reciprocity, mutuality and affective ties) developing in a different way online, in the absence of the direct, physical presence of the other.

As the FS is trying to measure whether participants “...enjoy close, empathic, supportive, caring friendships that are important to them; that they like and are interested in people; and that they enjoy interacting with others for its own sake” (Baron-Cohen & Wheelwright, 2003, p.509), it may be that a high score on the FS is achieving ‘deep structure’. It could therefore be hypothesised that individuals with ASC who use the internet and engage in online communication with others are more successful at gaining ‘deep structure reciprocity’ of friendships than those who are not using online communication as ‘affective sharing’ is mediated through written word (due to the nature of social media), which young people with ASC experience fewer difficulties with.

Research has shown that online communication can lead to closeness of relationships that could be described as ‘deep structure reciprocity’ for the typically developing population (Carpenter et al., 2018; Henderson & Gilding, 2004; Valkenburg & Peter, 2007). It could therefore be argued that the way friendships are formed online does not differ for those with or without ASC. Therefore, an individual with ASC who has been

able to form close, reciprocal friendships online is more likely to identify as non-autistic online, as there are no social parameters that have made them feel different from the general population. This is unlike face-to-face interactions where the influence of ‘affective sharing’ may lead to feelings of difference, which may cause someone to identify as an individual with ASC. This was also emphasised in the findings from phase two, where participants spoke of the internet giving them greater opportunities in term of meeting new people, including those who do not have autism.

It may also be that those who identify as non-ASC online are more likely to feel able to form close, reciprocal friendships. This could be due to those who have less ‘severe’ forms of ASC feeling more able to identify with a non-ASC population online (as they experience fewer differences) and therefore show an increased score on the FS. The original Baron-Cohen and Wheelwright (2003) study found that non-ASC males tend to score higher on the FS.

Many of the participants echoed similar statements in phase two to those cited in prior research in terms of social media alleviating time or eye contact related pressures. For example Benford and Standen (2009) outlined how online communication lessened “...*the emotional, social and time pressures experienced in offline situations*” (p.2).

It is important to note that most (57%) of the participants had ‘integrated’ their identities and no relationship was found between autistic identity (ADIS scale) and valuing friendships (FS scale). Therefore, many of the participants who scored highly on the friendship scale have scored highly on both the ADIS and the NADIS, while identifying as an individual with ASC online had no impact on friendship.

When addressing contemporary adolescents’ preferences for social media, Boyd (2007) considered properties of identity formation in an online, social media setting outlining

persistence, searchability, replicability and invisible audiences, which differ from identity formation when it occurs in a face-to-face social setting (see p. 39).

As argued in the introduction, all these factors may enable social interaction to become more concrete and less ambiguous. This may have a positive impact in reducing the social stress that those with ASC may experience (Bishop-Fitzpatrick et al., 2017; Müller et al., 2008). This could similarly make young people with ASC enjoy close, empathic, supportive, caring friendships (and score highly on the FS) and in turn feel that they identify more with a typically developing population (and score more highly on the NADIS).

Recent research has suggested that those who have experienced bullying in the past may be more likely to identify as an individual with ASC (DeNigris et al., 2018). One explanation for the lack of statistical associations between those who identified as an individual with ASC and the value they placed on close friendships could be due to some participants choosing not to seek close friendships to protect themselves from future bullying. Young people with ASC are less likely to recover from bullying or develop resilience due to difficulties in understanding the complex dynamics around bullying (Swearer, Wang, Maag, Siebecker, & Frerichs, 2012). Similarly, difficulties with ‘theory of mind’ (Baron-Cohen et al., 1985) have been reported to lead to difficulties in perception of bullying, as young people with ASC are more likely to perceive non-bullying situations as bullying (Eeske van Roekel, Scholte, & Didden, 2010). Similarly, one participant in phase two noted that social media use has prevented them from leaving the house, due to cyberbullying. The impact of social media addiction and cyberbullying has been well documented as having a negative impact on perceived social isolation (Primack et al., 2017).

Some participants in phase two spoke of social media use disrupting their sleep patterns, which is an area that is currently under research, predominantly within the university/college population. Some studies have suggested that there is a relationship between social media use and shorter sleep duration (Sampasa-Kanyinga, Hamilton, & Chaput, 2018). Another study found that social media use (specifically tweeting) was related to better quality sleep when taking place in the evenings, as opposed to late night social media use which was associated with lower quality sleep (Garett, Liu, & Young, 2018). It does appear that the relationship between sleep quality and social media use is complex, with one study focusing on social media stress clarifying that professionals should “...*focus on how adolescents perceive and cope with their [social media] use, instead of focusing on the mere frequency of [social media] use*” (van der Schuur, Baumgartner, & Sumter, 2018, p.1). It is also possible that other factors relating to social media could result in shorter sleep duration, for example ‘blue light’ which is given off by electronic devices such as mobile phone and tablets (Kessel, Siganos, Jørgensen, & Larsen, 2011).

Significance of findings:

Friendships have been theorised to be vital in terms of an individual’s development of positive self-image and self-competency (Hartup & Stevens, 1997). Therefore, if those who score more highly on the FS have developed friendships online, online communication would have assisted in the development of feelings of positive self-image and self-competency. This is important as typically, young people with ASC have been shown to have lower levels of self-esteem (Cooper et al., 2017; Jarrett, 2014). Some studies using self-report measures have implied that self-concept can mediate well-being for young people with ASC (Rodgers et al., 2018).

The reports from the participants in phase two show that there was a mix of views on the impact of social media on friendships. It is however clear that the majority of this group of participants were keen to highlight the positive impact and benefits of social media. Therefore, when working with young people with ASC, it may be appropriate to encourage young people to develop the skills to engage in the online community and meet others who have similar experiences to them. For example, through allowing young people to develop or maintain friendships through a medium that removes the social difficulties they experience (e.g. ‘affective sharing’) and where they feel they can identify with the population as a whole; this may have the potential to meet their need for close relationships (Mendelson et al., 2016).

Allowing young people with ASC to operate within an environment where there is less ambiguity and more concrete methods of communication (as outlined by Boyd, 2008), could enable these young people to develop their skills in interpreting the actions of others and thus assist development of theory of mind (Baron-Cohen et al., 1985).

Encouraging young people to use social media as a way of creating friendships that are close and meaningful over the internet could encourage individuals to identify with a typically developing population. Similarly, social media appears to provide young people with ASC with many opportunities that would not be available to them if they were not able to use social media. Primarily, it is a place where the difficulties they experience with social interaction are not evident to those who they are communicating with. Similarly, it gives them a place where they can form relationships with others with and without ASC. These skills could then be generalised to operating socially in a day-to-day environment. If the internet is used safely, responsibly and in moderation, there is a strong argument in that it could have a positive impact on the social development of

young people with ASC, as those who identified online with a typical population (and scored highly on the NADIS) were more likely to enjoy close, empathetic and supportive relationships (as measured by the FS).

4.3 RQ3: What is the relationship between digital identity and psychological well-being for young people with ASC (aged 14-19)?

A discussion of the qualitative and quantitative findings are shown in table 29. This is to demonstrate the findings from both phases alongside each other.

Table 29: Discussion of results relating to RQ3

| RQ3 | |
|--|--|
| Quantitative | Qualitative |
| <ul style="list-style-type: none"> • Correlational analysis showed no relationship between well-being (as measured by the Moods and Feelings Questionnaire; MFQ) and autism digital identity (as measured by the ADIS). This means that identifying as an individual with ASC online does not have a relationship with higher or lower levels of well-being. • Correlational analysis showed no relationship between well-being (as measured by the MFQ) and non-autism digital identity (NADIS). This means that identifying as non-autistic online does not have a relationship with higher or lower levels of well-being. • Of 84 participants, 45 were found to score 12 or higher (54%), which may indicate the presence of depression in the respondent (Angold & Costello, 1987). Studies have reported that a similar proportion of those with ASC experience mood disorders (e.g. anxiety and depression; 53%; Hofvander et al., 2009). It appears that the spread of mood disorders for this sample is similar to that of other studies carrying out research with those who are not social media users. This implies that social media use appears to have no negative or positive impact on well-being for young people with ASC. | <ul style="list-style-type: none"> • Most of the participants in phase two highlighted the positive impact social media has had upon their well-being, with four of the five participants having ‘higher well-being’ and ‘social support’ as key sub-categories discussed in the forum. • When participants spoke of their higher levels of well-being, it appeared to be related to opportunities for low stress social communication and gaining support from peers. • One participant of the five appeared to have had more negative experiences online, with ‘lower well-being’ and ‘difficulties with online friendships’ appearing in the participants forum contributions. |

Interpretation:

In phase one, no correlations were reported between well-being and digital identity. As it appears that the number of participants the MFQ indicates the presence of a depression for in this sample is similar to that reported within other studies (Hofvander et al., 2009), it can be argued that there is no relationship between internet use and the well-being of young people with ASC. However, within this study there was no control group involving young people who do not use social media to make a comparison, nor has there been access to data from previous studies, so this finding should be interpreted with caution.

The relationship between social media and self-esteem has been reported to depend on the individual's type of engagement with social media, as they may be using it to become more involved in their community, which has shown to have a positive impact on self-esteem, or for social comparison which has shown to have a negative impact (Valkenburg et al., 2006; Vogel et al., 2015; Wood et al., 2016). If this is also the case for well-being, it could explain why there was no relationship found between internet use and wellbeing in the ASC population sampled. Evidence to support the importance of the nature of social media engagement on well-being can be found by considering the research on the 'Facebook' platform. This has shown use of 'Facebook' to predict subjective decline in well-being, through social comparison, leading to envy and depression (Appel, Gerlach, & Crusius, 2016; Kross et al., 2013; Verduyn et al., 2015). Conversely, another recent study found higher levels of happiness for young people with ASC who used 'Facebook' compared to those who used 'Twitter' (Ward, Dill-Shackleford, & Mazurek, 2018). If some participants were engaging in social media in a way that supported higher levels of well-being (e.g. involvement in the online ASC

community) and others engaged in a way that had a negative impact on their well-being (e.g. internet addiction), the results would not show consistent trends and no statistical associations would be found. A wide range of impacts were reported in phase two, and standard deviations were relatively high, indicating the wide range of scores obtained.

Positive Emotional and Psychological Well-being

In phase two, when participants spoke of their higher levels of well-being, it appeared to be related to opportunities for social communication. For example one participant noted; *“I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it.”*. Similarly, another participant noted *“Online has been my main method of social interaction, and therefore my activity online has been vital for my social well-being and happiness”*. This would appear to be congruent with the research that has suggested experiencing difficulty with social interactions can play a central role in the development of well-being (Rumney & Macmahon, 2016), while social interaction has been highlighted as a lifelong need (Baumeister & Leary, 1995; Rueger et al., 2016). If individuals with ASC can meet this lifelong need for social interaction through the use of social media, then it could result in higher levels of well-being for some individuals who use it appropriately.

Another participant noted a preference for using online communication for social communication (see page 103). It appears for some young people with ASC, the online world has provided them with vast opportunities for social communication, which they feel has had an impact on their well-being.

When participants spoke of the ‘social support’ that online communication has given them, it was generally around the increased understanding that meeting others online would be able to bring. For example, one participant noted; *“I felt like there were*

people online who understood my quirky and unusual ways and felt the same. it was nice to feel like I fitted in somewhere”. It is noted by researchers that the neurodiversity movement seeks to create a community of people who can provide mutual support, self-advocacy as a community and a celebration of neurological difference (Kapp et al., 2013). The qualitative findings from this research would support the positive aspects outlined in the neurodiversity movement.

Another participant spoke of the ‘social support’ they found in their social media use, by noting; *“I know for a fact I wouldn't be here if it wasn't for the times my friends went out of their way to talk me out of things, as I hope I did with them”*. Young people with ASC may be able to not only mediate the sensory overload that comes with social communication but also to discuss their experiences in a constructive way that provides strategies for the future. If while mediating the sensory overload, young people with ASC are then able to access social support it can be hypothesised that this will provide these young people with protection against mental health difficulties, as social support has shown to be a protective factor against mental health problems (Siedlecki, Salthouse, Oishi, & Jeswani, 2014; Trujillo, Perrin, Sutter, Tabaac, & Benotsch, 2017).

Reduced Levels of Emotional and Psychological Well-being

Other studies on individuals with ASC have found that depression levels increase with age and IQ (Ghaziuddin et al., 2002; Vickerstaff et al., 2007). Many of the participants in the study were bloggers and were articulate in expressing their views, so it could be hypothesised that these participants are at higher risk of mental health problems, due to their increased cognitive processing capabilities. It is also important to note that generally, mental health problems become more severe in the adolescent period and there is a high risk of continuation into adulthood (Merikangas et al., 2009). However,

this does not appear to have been reflected in higher levels of depression for this sample.

Prior research has shown that people with ASC are significantly more likely to experience low levels of well-being compared to a typical population (Danker, Strnadová, & Cumming, 2016; Ghaziuddin, 2005) and although internet use appeared to increase opportunities for social interaction for the participants in this study, it did not appear to have had a knock-on effect on some of the participants' well-being.

One participant spoke of the negative impact social media has had on their well-being. This participant's quotes could be found in 'low well-being' and 'difficulties with online relationships'. In these sub-categories, the participant spoke of internet addiction and cyber bullying (see p. 118).

Internet addiction is included in the DSM-V as a disorder (American Psychiatric Association, 2013), and involves online and/or offline computer usage and includes at least three subtypes; excessive gaming, sexual preoccupations, and e-mail/text messaging (Block, 2008). Block (2008) outlined how internet addiction must contain four key components;

- *Excessive use*; often associated with a loss of sense of time or a neglect of basic drives.
- *Withdrawal*; including feelings of anger, tension, and/or depression when the computer is inaccessible.
- *Tolerance*; including the need for better computer equipment, more software, or more hours of use.
- *Negative repercussions*; including arguments, lying, poor achievement, social isolation, and fatigue.

This participant may have been experiencing internet addiction as outlined by the DSM-V, which has been shown to have many well-documented comorbid difficulties and

consequences for the mental health of those who are affected (Block, 2008; Lu et al., 2017; Pugh, 2017; Schimmenti et al., 2017).

Significance of findings:

As these results implied no link to well-being; arguably internet use should neither be encouraged nor discouraged for young people with ASC. Type of internet use (e.g. duration, different social networking sites) and its impact on well-being needs to be explored further in future research.

If a young person can use social media to fulfil their need for social interaction, which they otherwise would find difficult due to their social communicational difficulties then young people should be encouraged to use social media in this way. Young people must be taught how to utilise online friendships and be part of a community safely, especially given this group's vulnerability, particularly in relation to understanding the exaggerated social norms that come with the internet (see psychological well-being and social media section on pp. 55-56; Rost et al., 2016; Waskul, Douglass, & Edgley, 2000).

It is clear from prior research that giving young people choices and control over their lives will have a positive impact on well-being (Apland, Lawrence, Mesie, & Yarrow, 2017; Kohn, 1993). Following further investigation on the type of social media use and its relationship to well-being, supporting young people in using social media must be led by the young people themselves and their views on how it helps or hinders their well-being should be held at the centre. The lack of statistical findings and large variation of data further imply that the association between an individual's social media use relationship and their well-being is complex and must be explored further.

It is important that young people are provided with skills enabling them to protect themselves from internet addiction, as there are many highlighted negative impacts on well-being (Block, 2008; Lu et al., 2017; Pugh, 2017; Schimmenti et al., 2017). Young people with ASC appear to be at significant risk of developing internet addiction compared to a typical population (So et al., 2017), so it must be monitored with a higher level of attentiveness for the ASC population.

4.4 RQ4: Do young people with ASC (aged 14-19) feel social media enables their life outcomes?

A discussion of the qualitative and quantitative findings are shown in table 30. This is to demonstrate the findings from both phases alongside each other.

Table 30: Discussion of results relating to RQ4

RQ4:

| Quantitative | Qualitative |
|--|--|
| <ul style="list-style-type: none"> • A positive correlation was found between identifying as an individual with ASC online (a higher score in the ADIS) and believing that social media will have a positive impact on the chances of meeting new friends or getting in a relationship (a higher score in the LOr). This would imply that individuals who identify as having ASC online are more likely to believe that online communication raises their chances of forming relationships (both friendships and a partner). Alternatively, those who believe that online communication raises their chances of forming relationships (both friendships and a partner) may be more likely to identify as ASC online. • No correlation was found between identifying as an individual with ASC online (a higher score in the ADIS) and believing that social media will have an impact on the chances of achieving at school or gaining and retaining employment. This implies that if a young person identifies as autistic when online, their view on the internet's ability to enable them to achieve at school or gain and retain employment will not be affected. • A negative correlation was found between identifying as non-autistic online (a high score on the NADIS) and believing online communication will increase chances of making friends or finding a relationship (a high score on the LOr). Therefore, if a young person identifies as non-autistic | <ul style="list-style-type: none"> • During the forum-based discussion, the participants chose to contribute least to the 'Life Outcomes' thread. This could imply that they do not have as many views regarding their future life outcomes as they do on the other outlined subjects (friendships and well-being). However, in this part of the forum, all participants spoke of the internet providing them with further opportunities relating to 'Life Outcomes'. The responses were divided into two sub-categories; 'confidence' and 'employment opportunities'. • One participant noted that they would not have the confidence to approach an employer in person, but they are able to online. • Other participants noted that the internet has provided further employment opportunities, due to feeling more comfortable in communicating online. |

online; they are less likely to believe that their chances of making friends or get in a relationship is positively affected by online communication.

Alternatively, those who feel that online communication raises their chances of forming relationships (both friendships and a partner) may be less likely to identify with as non-autistic online.

- A negative correlation was found between identifying as non-autistic online (a high score on the NADIS) and believing online communication will increase chances of achieving in college and gaining/retaining employment (a high score on the LOw). Therefore, if a young person identifies as non-autistic online; they are less likely to believe that their chances of achieving in college and gaining/retaining employment are affected by online communication. Alternatively, though who believe that online communication will increase chances of achieving in college and gaining/retaining employment are less likely to identify as non-autistic online.
-

Interpretation:

It is important to note that the ‘life outcomes’ scales are measures of a young person’s views of how online communication will impact on their life outcomes. They are not measuring life outcomes themselves (e.g. success in college/employment, quantity and quality of relationships). This was unlike the ADIS, NADIS, FS and MFQ; all of which create a formulation of the young person’s feelings around identity, friendship or well-being through a larger list of related questions. This explains why there was no significant correlation found between identifying as ASC online and the FS (which measures enjoying close, empathic, supportive, caring friendships); yet there was a

significant correlation found between identifying as an individual with ASC and believing the internet will impact your life outcomes with regards to relationships.

The ‘Life Outcomes’ questions were directive in their approach, for example they were asked to rate the following question on a Likert scale; “*Through online communication, I am more likely to find employment*”. Each ‘Life Outcomes’ Scale was formulated from two questions. The other scales were formulated from 12 or more items.

It is also important to note that people with ASC have been found to have difficulties making future predictions, so it may be harder for this population to interpret online communications effect on their life outcomes (Hutchins & Prelock, 2018; Lind & Bowler, 2010; Lind, Williams, Bowler, & Peel, 2014; Lind, Williams, Raber, Peel, & Bowler, 2013; Terrett et al., 2013).

Similarly, people may have been exposed to a variety of different viewpoints when discussing the positives and negatives of social media. Someone will likely hold very different views depending on whether they have been exposed to the online neurodiversity community (which emerged online and have empowered many young people with ASC; Kapp et al., 2013), or recommended guidance for schools (which generally focuses on staying safe online and the risks attached to the online world; Autism Toolbox, 2018).

Similarly, as commented in RQ2, many young people with ASC who use online communication frequently see it as something that enables them to form relationships that they otherwise would not be able to. In phase two many of the participants spoke about finding it easier to communicate with potential employers, which will have a positive impact on their ability to find employment.

Within virtual communities, the creation of an online profile coupled with the formation of new social networks will impact directly on expression of identity and therefore how identity is performed and reinforced (Greenhow & Robelia, 2009). Research has shown a link between social functioning and identity formation (Crocetti, 2017). Therefore, if someone has formed an online identity and it has been performed and reinforced through their social functioning, it would explain why they believe that their life outcomes in terms of relationships have improved due to social media, as it is part of their identity.

Access to a strong social support network has been shown to be a strong determining factor in the well-being of people with ASC (Renty & Roeyers, 2006). Therefore, those who identify as autistic online are likely to be more involved in the autism or neurodiversity community, they may be more likely to be receiving online social support which may in-turn improve levels of wellbeing. As well-being and relationships have shown to be linked (Davila et al., 2017), it could explain why this population feel that online communication comes with this perceived positive impact on their relationship outcomes.

Frequent users of social networking have also been shown to exhibit greater social trust and higher levels of civic participation (Choi & Shin, 2016; M. Skoric et al., 2015; Valenzuela et al., 2009). Increasing civic participation in an area of interest could increase the employment opportunities, as research carried out in Sweden has suggested occupational contact networks reduce unemployment risks (Hällsten, Edling, & Rydgren, 2017).

It could also be hypothesised that those who identify more strongly as ASC online could be characterised as those who have more 'severe' forms of ASC (see table 1), although

there is no evidence from this study that this is the case. Some families have reported using social media as a tool to adapt to their child with a disability (or condition), improving family relationships (Nally et al., 2000). If a young person with a more 'severe' form of ASC (which meant they identify as an individual with ASC more highly) was able to maintain better relationships with their friends and family, they could be more likely to perceive online communication increasing their chances of forming relationships. The relationship between identifying as an individual with ASC online, 'severity' of ASC and how it relates to ability to form friendships through computers may be worthy of future research.

There have been employment programmes targeted at individuals with ASC that have found particular success for individuals gaining jobs related to technology and computers (D Hedley et al., 2016; Howlin et al., 2005). In some blogs, parents of children with ASC have spoken about how they feel digital communication may aid their children's future employment chances (Microsoft Corporate Blogs, 2015), although it must be noted there could be bias as these blogs have been published by Microsoft who will want to look like inclusive employers as it would promote their brand. Employers have also written papers on how to employ people with disabilities (or conditions), highlighting online communication as an effective way of doing this (New Co-Investigator, 2013). However, there was no link between autistic identity and young people with ASC believing that they are more likely to gain/retain employment due to social media, although some participants in phase two had been able to recognise the potential advantages. This either means that the population as a whole are not aware of the employers presenting these opportunities, or the participants have not yet accessed or been able to access these new opportunities.

Those who identified as non-autistic appear more likely to feel that the internet will have no effect on their chances of forming a relationship. This could be related to the issues around internet addiction and loneliness/isolation (Bahrainian et al., 2014; Lu et al., 2017; Sharifpoor et al., 2017), which would decrease opportunities for forming new friendships.

If someone identifies as non-autistic online, they may be seeking more opportunities to engage with a typical population, which may, for example, put them at higher risk of cyber bullying, as young people with ASC typically are (Carrington et al., 2017). This risk may make young people with ASC who identify as non-autistic believe online communication is having no positive impact on their life outcomes.

The difficulties relating to internet addiction and social isolation (Müller et al., 2008; Schroeder et al., 2014), may be why this population feel that online communication will have no positive impact on their ability to gain and retain employment/achieve at school.

Internet addiction has been shown to have a significant negative impact on academic achievement for young people (Skoric, Teo, & Neo, 2009; Stavropoulos, Alexandraki, & Motti-Stefanidi, 2013). If there are no concessions made for young people in terms of their ability to learn through online communication, yet the research and teaching in schools suggest that social media has a negative impact, it would explain why young people would feel this way. However, the research does suggest that the skills acquired from online communication use can be transferred to employment, particularly as computer/internet skills have shown to increase employability (Mascheroni & Olafsson, 2016), but the participants in this study may not be aware of this as many will not yet be of employment age.

Significance of findings:

If people who identify as an individual with ASC online feel that social media meets their lifelong need for social interaction (Baumeister & Leary, 1995; Rueger et al., 2016), which allows the identity to serve as a protective mechanism, raising levels of personal self-esteem and the self-esteem in the community one identifies with (Cooper et al., 2017), then it should be encouraged.

As young people who identify as an individual with ASC do not feel that online communication increases their employment opportunities, it could be argued that it is vitally important that educators provide young people with ASC extra training in operating the online world. This is because it is an area where people with ASC are not as disadvantaged due to their social communicational difficulties and the pressures that come with them, as these are mediated by social media use. Recent research has shown that technology can have a positive impact on helping individuals with ASC to reach employment-related outcomes (Damianidou, Arthur-Kelly, Lyons, & Wehmeyer, 2018).

However, the qualitative findings of this research imply something different; that there is space for online communication to have a positive impact on the life outcomes of young people with ASC, particularly with regards to job opportunities. There does not, however, appear to be a clear picture of how this could be implemented by others or how these opportunities could be communicated to young people with ASC, so they are able to utilise them. Phase two findings therefore indicate that individuals with ASC believe technology has a potential positive impact on employment, so there is scope for further research into implementation of online communication-based recruitment and employment programmes for young people with ASC, where the young people's views and needs are at the centre of planning.

Studies with typically developing populations have indicated that “*children who benefit from a greater autonomy of use [of the internet through mobile phones] and a longer online experience [are] reaching the top of the ladder of opportunities*” (Mascheroni & Olafsson, 2016, p. 2), meaning young people who have had more experience with the internet will have more opportunities to achieve success with regards to life outcomes and employment. If this is an area where many youngsters with ASC are not dis-advantaged, then educators must provide them with the tools that they need to achieve future life successes.

4.5 RQ5: What is the relationship between age and digital identity, ability to form meaningful relationships, psychological well-being, and feelings that social media enables life outcomes for young people with ASC (aged 14-19)?

Discussion:

From statistical analysis, there was no significant relationship between age and any of the following: digital identity, friendships, psychological well-being and views on life outcomes. This would imply that the findings of this study are applicable to all ages involved in the study (from 14-19).

Interpretation:

Some studies have suggested that use of social media over time can have an impact on digital identity development, arguing that when an individual uses a social media platform they are entering a shared, predefined, cultural world to which one tends to adapt (Manzi et al., 2018). Other studies have suggested that younger adolescents experiment more frequently than older adolescents with their digital identity online (e.g. exploring how others react to them) to facilitate social interaction (Valkenburg, Schouten, & Peter, 2005). However, this does not appear to influence whether an individual identifies as an individual with ASC or non-ASC, as no correlation was found between age and digital identity.

There does not appear to be a significant correlation between age and the ability of young people with ASC (aged 14-19) to enjoy close, empathic, supportive, caring friendships with individuals that are important to them; to like and be interested in people; and to enjoy interacting with others for its own sake (Baron-Cohen &

Wheelright, 2003). Some prior researchers have argued that the nature of friendships change over time, with older adolescents becoming less popular and known by fewer people over time (Felmlee, McMillan, Rodis, & Osgood, 2018). It is also important to note that this research was completed on a USA population, who experience transition to high school that was noted as a factor in this. In a different school system, for example the UK, this may not be the case. These results suggest that young people aged 14-19 will still desire friendships regardless of social media use.

Some studies have suggested a relationship between age and well-being. It is important to note that generally, mental health problems become more severe in the adolescent period and there is a high risk of continuation into adulthood (Merikangas et al., 2009). Online activity does not appear to have any effect on this.

Adolescent views of life outcomes related to internet use appear to note change depending on the participant's age (14-19). Some have suggested that work-related outcomes can differ depending on the age of the participant (Andre, Van Vianen, Peetsma, & Oort, 2018). However, this study suggests that there is no further impact from social media use on an adolescent population.

Significance of findings:

These results suggest that individuals with ASC aged 14-19 years, are at no increased risk of social media use effecting their ability to enjoy friendships, well-being or views on their life outcomes. The opportunities outlined in RQ1-4 should be encouraged for adolescents aged 14-19, as the findings indicate they are as effective across the adolescent period.

4.6 RQ6: What is the relationship between gender and digital identity, ability to form meaningful relationships, psychological well-being, and feelings that social media enables life outcomes for young people with ASC (aged 14-19)?

Discussion:

From statistical analysis, there is no significant relationship between gender and any of the following areas; digital identity, friendships, psychological well-being and views on life outcomes.

This would imply that the findings of this study are as applicable to males, females and ‘other’ (transgender man, transgender woman, gender binary, gender fluid, etc). There were eight participants who identified as ‘other’, so to fully interpret the situation for this demographic, there may need to be more in-depth research focusing on this population specifically as there are too few participants to generalise results from.

Interpretation:

Gender has been shown to have a notable impact on digital identity development for adolescents (English & Johns, 2016), but this does not appear to have had an impact on ASC identification.

In the original study involving the friendship questionnaire, a significant difference was found between males and females with ASC (Baron-Cohen & Wheelwright, 2003).

However, this was not evident within this study, although the inclusion of ‘other’ is likely to have had an impact on the results. This could imply that young males with ASC demonstrate a higher need for friendships when using social media. This could be due to the difficulties that young boys with ASC often experience relating to social

communication, which are alleviated by the differences in online communication (for more information see RQ2 discussion; p. 132). It has been reported that females with ASC are often better at masking these differences due to increased social communication skills (Lai et al., 2011), so it may be that the gender differences are less prevalent when communicating online, which is why there is no significant difference.

Research has shown that generally women score higher than men when it comes to internalising disorders such as anxiety or depression (Bogren et al., 2018; Gater et al., 1998; Hankin, 2009; Macleod et al., 2007), which appears to be applicable to a population with ASC (Cai et al., 2018). Some research has suggested males are more likely to engage in externalising behaviours such as hyperactivity, aggression or rule breaking (Boyd et al., 2015; Matos et al., 2017), which can be associated with externalising disorders such as Attention Deficit Hyperactivity Disorder or Oppositional Defiant Disorder (American Psychiatric Association, 2013). However, in terms of anxiety or depression, recent research has suggested for young people with ASC that there is no gender related difference in well-being for self-report or parent report, congruent with the findings of this study (Begeer et al., 2017). Further research may be needed to unpick the difference for young people who identify as ‘other’ (transgender man, transgender woman, gender binary, gender fluid, etc), as typically this population have been shown to be at higher risk of mental health difficulties (George & Stokes, 2018).

Significance of findings:

These studies imply that the gender of an individual neither increases nor decreases the risks and opportunities associated with social media use for young people (aged 14-19) with ASC.

However, the results for those who identify as 'other' must be approached with caution due to the small number of participants.

4.7 Contribution to knowledge

The findings from this study present a mixed picture of the impact that social media can have on young people with ASC. The findings and views from participants' tentatively suggest that social media has had a positive impact on their lives.

Young people with ASC have been described as vulnerable in many areas, particularly socially (Sofronoff, Dark, & Stone, 2011). It is clear that offline vulnerability can be transferred to online vulnerability, and with internet use being an under-researched area, there is little infrastructure to protect those at most risk (Livingstone, 2013). In this fast-changing landscape, understanding how online communication can have a positive (and negative) impact on young people from their own personal experiences is vital in shaping policy and creating online infrastructure to support and protect future generations.

This study has provided a clearer picture of the potential benefits social media can have on the lives of young people with ASC. The results of this study should be interpreted within the research already available regarding risks of online use, but the opportunities outlined in this final section must be recognised when supporting young people with ASC to understand the online world.

4.7.1 Internet use/addiction

The distinction between internet use and internet addiction needs to be discerned when interpreting these findings. Internet addiction has been shown to have many well-documented comorbid difficulties and consequences for the mental health of those who are affected (Block, 2008; Lu et al., 2017; Pugh, 2017; Schimmenti et al., 2017).

However internet use is commonplace for many people across the world, with empirical

research showing that a significant number of internet users spend several hours online every day (Court, 2016; Eynon & Malmberg, 2011; Selfhout et al., 2010). When talking about moderate internet use, we are speaking of the latter, which is a regular activity for a high proportion of the population.

This could be likened to the research with the ASC population around special interests (which highly occur within this population), as previous research has found a positive link between motivation to engage with special interests and subjective well-being, along with satisfaction across specific life domains including social contact and leisure. Contrary to this, a link has been found between high intensity special interests and low levels of subjective well-being (Grove et al., 2018). Therefore, with both special interests and internet use, they may be healthy to encourage for young people with ASC, but in moderation.

4.7.2 Digital identity

When a young person frequently uses social media, it will impact their identity development, as personal construct psychology indicates that identity is affected by the systems within which we interact (Kelly, 1955; Landfield, 1980). It appears that online, young people have been able to develop their digital identities in the way that they choose and feel is appropriate for the circumstance, both ASC and non-autistic. Many of these young people may be seeing the online world as a 'safe place' for identity development, where they are not judged for their differences. This study has reported that use of online communication supports young people with ASC in developing an integrated online identity, where they identify with both the ASC and non-ASC communities.

Similarly, if young people are using social media and it is developing both their ASC identity by becoming involved in movements such as neurodiversity (Kapp et al., 2013) while simultaneously developing their identification with a typical population (as the majority of the participants in this sample had), the potential positive impacts both online and offline could be significant, as both ASC and non-autistic identity have been shown to have a positive impact. Nonetheless, the findings from this study further emphasise how identity development for young people with ASC could be a ‘protective mechanism’ against social isolation if it enables them to identify with the wider non-ASC population, while retaining their ASC identity and ability to identify with those with ASC (Cooper et al., 2017).

4.7.3 Friendships

As originally suggested by Blume (1997), many of the participants felt that the online world has provided them with “*vast opportunities for exchange*”, that they may have not otherwise have had access to without the internet.

The findings from this study suggested that those who use online communication and identify more with a typical population online are likely to show higher desire for close and intimate friendships. Therefore, if a young person with ASC identifies more with those without ASC, correlational analysis suggests they show an increased motivation to connect with others online.

Qualitative analysis clearly demonstrated that young people feel that the internet provides them with opportunities to socialise, which has resulted in increased desire and opportunity for friendships online. If social media provides young people with ASC a sense of belonging and community which is arguably a human need (Erwin & Phil,

1993; Mendelson et al., 2016), then the positives are clear and young people with ASC should be encouraged to develop their social skills online.

4.7.4 Well-being

This study implied that the relationship between internet use and well-being is unclear. The findings do suggest a wide variance of impact, implying well-being is linked to the type of internet use that a young person is engaging with (e.g. active or passive use; Verduyn et al., 2017). However, it does appear that young people with ASC who are internet users are not experiencing lower levels of well-being than the general ASC population as the percentage of those reaching the threshold on the MFQ appeared to be average for this population; implying internet use does not have a significant effect on well-being.

However, the qualitative findings (and findings from RQ2), imply that young people feel that the internet has provided them with opportunities to gain extra social support from others who they feel understand them, through a way of communicating that is not stressful. Social support has shown to be a protective factor against low-levels of well-being for those with ASC (Siedlecki et al., 2014). Therefore, seeking social support should be encouraged providing it is sought through safe passages. Those who report the internet increasing their levels of well-being, generally referred to the increased opportunities for social communication; *“I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it.”*

The qualitative findings further emphasised the differing impact social media can have on young people. For example, one participant further emphasised the negative impact of internet addiction and isolation (see p. 117).

4.7.5 Life outcomes

Through correlational analysis, this study suggested that those who identify with a typically developing population state that the internet is unlikely to affect their life outcomes with regard to relationships and job/college opportunities. Arguably, this could be due to the risk-based approach to training young people in using social media. Further research needs to be carried out to explore the impact of positive training (i.e. training young people how to use social media, rather than how not to use) on young people's views of their life outcomes.

The results from this study imply that those who identify as an individual with ASC feel online communication will have a positive impact on their life outcomes with regards to relationship formation.

However, the young people who identified as an individual with ASC did not believe that the internet would provide them with further job opportunities. There have been employment programmes targeted at individuals with ASC that have found particular success for individuals gaining jobs related to technology and computers (D Hedley et al., 2016; Howlin et al., 2005). It appears that some young people were able to recognise this, with some participants in the forum noting that they have experienced increased employment opportunities. Educators may need to provide more ASC specific strategies to support young people in understanding how to use online communication to increase their life chances.

4.7.6 Age/Gender

The findings from this study indicate there is no further risk attached to a young person based on their gender, or age within the adolescent period (14-19). Therefore, these findings can be generalised to those within the outlined ages and males and females (it is important to note there are too few participants who identified as ‘other’ to generalise results to this group).

4.7.7 Weaknesses/areas for future research

Prior research that has focused on a medicalised views of disability (e.g., physical disability) has found through qualitative analysis that individuals revealed their disability depending on the demands of the context and relevance of the disclosure (Anderberg & Jönsson, 2005). This could apply to the ASC population when exploring digital identity, as the participants may have felt that they had to identify as either autistic or non-autistic, depending on where they had received the link to the survey from (some responses were from ASC advocate groups). With this type of volunteer sampling, social desirability effects must be acknowledged.

This piece of research was focused on the views of the young person, but did not acknowledge the views of others around them. Mendelson et al., (2016) noted that the self-reported relationships from young people with ASC were of lower quality than when they were evaluated by their peers or family. To gain a more accurate understanding of the quality of a young person’s friendships, seeking information from a variety of sources may provide a deeper insight.

The majority of participants in this study were recruited through online fora, where it has been noted that young people have been able to create an identity and image of how

they see themselves and how they want others to see them (Williams & Merten, 2008). Others have argued that many view the online world as a phenomenon where “...*whoever is not available on the internet does not exist*” (Feher, 2015, p. 138), and people are quick to create alter egos of themselves (Feher, 2015). The young person’s views of themselves may be different online and offline, which may make it difficult to apply these findings to the teaching of online skills in the offline world. There may also be issues with reliability of the information provided by participants, as they may have not always been telling the truth/they may not be who they say they are.

During phase 2 data collection when views of individuals with ASC were sought on the online fora, participants were informed that there would be a prize draw for a £30 Amazon voucher for a user that participated extensively in the discussion. It is important to note that although providing a financial incentive encouraged participants to engage in discussion, it may have also encouraged them to engage in a way that they would not have done so without the incentive (e.g. saying things that are not strong opinions of theirs to fill up words). Therefore this must be noted as a limitation in this phase of data collection.

The digital identity scales (ADIS and NADIS) were designed for deaf acculturation and adapted for ASC. Although there were good levels of reliability, this measure has not yet been used or interpreted as digital identity in another study. There is also little clarity around the difference between online identity and offline identity for those with ASC. It could be argued that due to the ‘rigid thinking patterns’ outlined in the ASC criteria in the DSM-V (American Psychiatric Association, 2013), young people with ASC are considerably less likely to create an online alternative identity. Although this study found that young people with ASC who use social media are likely to form an

‘integrated’ identity, ‘rigid thinking patterns’ may mean their digital identity and offline identity may be no different, and their ‘integrated’ identity may have formed in the offline world. The difference between online and offline identity for young people with ASC could be an area worthy of future research.

The digital identity scales (ADIS and NADIS) used some language that may have not been clear to some of the participants. For example, it was asked ‘how well do you know about...?’ (for full questionnaire see appendix 4). This use of language may have been unclear to participants and therefore affected the validity of their responses. More carefully worded items that had undergone extensive piloting would guard this limitation.

The life outcomes questions were answered on a Likert scale, which may present difficulties in interpretation, as the scale was not checked for reliability due to the small number of questions. This part of the research could have been more reliable if a standardised questionnaire was available exploring the views of young people relating to their life outcomes, however no such measure was available.

It is important to note that people with ASC have been found to have difficulties in thinking about and predicting their future, so it may be harder for this population to interpret the effect of online communication on their life outcomes (Hutchins & Prelock, 2018; Lind & Bowler, 2010; Lind et al., 2014, 2013; Terrett et al., 2013).

Therefore, what young people with ASC think that the effect online communication will have on their life outcomes could be very different to the genuine effect online communication will have. A longitudinal study that aimed to understand the relationships between internet use and its real-life impacts on relationships and jobs outcomes would provide further clarity.

Prior research has emphasised the complex relationship between well-being and social media use (Wang et al., 2017), although no study has yet looked into digital identity and well-being. However, this study looked into the social media use with regard to well-being no deeper than prior studies, so it could somewhat be expected that no clear relationship was found between digital identity and well-being. Further research needs to clarify different types of social media use (e.g. engaging with a community, social comparison, active or passive use; Verduyn et al., 2017) and digital identity to correlate with a more in-depth understanding of well-being.

No comparison group was used in this study, meaning the findings cannot be compared to a similar group of young people who do not use social media. This means it is difficult to draw conclusions about the effect of social media use on a young person's functioning and consider how it may be different had they not been using social media. A future controlled study using an experimental and matched comparison group would enable specific research questions about the impact of regular social media use to be explored.

All the participants recruited through the offline world were from a specialist provision and no participants recruited in this way were from mainstream schools. Although mainstream schools were approached, they reported to me that no consent forms were returned by parents. A future study with a more varied sample from the offline world would be more representative of young people with ASC in the United Kingdom.

This study has shown a clear picture of the vast potential positive impact that social media is having on the lives of many young people with ASC, as well as clarifying some of the risks attached. This must be explored further, holding the young people's

views at the centre, whilst ensuring a positive approach to towards teaching use of social media is implemented in the future.

Chapter 5: Implications for Educational Psychology (EP) practice

5.1 Digital identity

Participants in this study described the online world as a place where they could share strategies for use in the offline world. If young people can be supported to create responsible and regulated areas where they can share advice, the potential positive impact could be extensive. Many online areas have begun to emerge that are more rigorously regulated, such as the National Autistic Society online fora for young people, or the ‘Wrong Planet’ forum (National Autistic Society, 2018; Wrong Planet, 2014). In these fora, moderators ensure that there clear, publicised rules for posting and any posts that violate these rules are removed.

Many of the participants from the current study were also bloggers and are engaged in a safe community of people writing about their experiences as a person with ASC. As these areas develop that minimise the risk to the vulnerable, there is a clear rationale for encouraging young people to use them. Arguably, the ASC community have begun to create an online infrastructure to support their community (Livingstone, 2013), which can enable them to use the internet safely and responsibly as a group.

In EP practise, it is often recommended that young people who have recently received a diagnosis of ASC or are having ASC related difficulties at school seek the support from a local community/advocacy group. A good example of this is an organisation called Autism Berkshire (Autism Berkshire, 2018), who receive funding from a number of the local authorities in the Berkshire area. This organisation regularly runs support groups for teens with ASC where they can meet and share experiences.

As EPs, we seek to provide support and recommendations drawing on the evidence-base in psychological theory and research. Research conducted by EPs has been limited with regard to social media use, however this study has extended the research base and our understanding about the risks and opportunities involved. The implications for EP practice are emergent but there are some promising implications arising from this research. For example, encouraging young people to be involved with local advocacy groups may help to extend their identification with both ASC and non-ASC populations. It is likely that there is value in identifying with both populations in both an online and an offline world.

5.2 Friendships

Participants frequently acknowledged their preference for online communication, with one participant noting

“Being online means that I can talk to people when I have the energy to, and they won't necessarily mind if I need to step away for an hour or a day or so, whereas a person in real life may look at me weirdly if I were to walk away in the middle of a conversation.”.

If there is a large proportion of young people who find this method of communication easier, the question that could be put to critics of social media use was framed by Phillipa (case study 1) as follows: *“Why should I force myself to socialise at neurotypical standards if that creates high anxiety?”*. It could be argued that due to the prevalence of social media being used for communication within society as a whole, communicating in this way goes beyond a ‘neurotypical standard’ and many young

people without ASC may also choose to form their friendships through online communication.

Young people with ASC are at higher risk of anxiety (Strang et al., 2012) and school refusal (Kearney, 2008). Often an EP will be supporting a young person, school or parent/carer to manage the difficulties that frequently co-occur with ASC. Anxiety management strategies, such as graded exposure (Lang, Mahoney, El Zein, Delaune, & Amidon, 2011) are therefore important to incorporate into interventions to support a young person to re-integrate back into school. Digital technology can be used, for example within a re-integration plan for a young person with ASC who has high levels of anxiety about school attendance. For example, EPs could develop interventions with teachers, by setting group tasks with social involvement provided through online communication. This approach has the potential to help the young person with ASC to build group identity with their peers at school by utilising social media to aid communication and build relationships. Group identity developed through online interaction with peers at school can then be gradually moved offline in a graded way. This could involve moving online interactions towards face-to-face interactions, initially in a very limited way (e.g. one group task a week in a chosen area of school), gradually working towards full integration over a defined period of time. This process has the potential to impact on the development of relationships, providing access to friends from the non-ASC community.

5.3 Well-being

This study found no correlation between digital identity and well-being. The implication is that there may be as yet undiscovered mechanisms in the way a young person's

identity develops online, so social media use should neither be encouraged or discouraged but its impact evaluated on an individual basis. It is important for EPs to be aware of the fact that some of the wider public assumptions made about the problems with internet access may be different for young people with ASC. Phase 2 of this research indicated that there is scope for social media to have a positive impact on the lives of young people with ASC and although this does not independently contribute to changing EP practice, it further supports the suggestions made in previous sections (5.1 and 5.2).

5.4 Life outcomes

As noted in section 4.7.5, individuals with ASC who identify with a non-ASC community are less likely to believe the internet will increase their future opportunities with regard to college and employment. Young people who are users of the internet and social media are likely to have developed skills to be able to use technology competently, yet may not see how this could benefit them in their future lives.

EPs often adapt a strength-based approach when supporting a young person, their parents/carers and school (Bozic, 2013). EPs and schools may therefore wish to adapt more freely a strength-based approach towards working with young people with ASC who are users of social media, as their skills can be transferred towards learning (as they could engage in learning online) and employment, through giving them opportunity to explore jobs across the internet that could utilise their areas of strength. If these young people are able to see how their skills could benefit them in their future and create their own goals, they are more likely to achieve success (Law, 2013).

Another implication for EP practice relates to individuals who identify as ASC online. It will be important to find out what their goals relating to relationships (romantic and friendship) and achievements in school/college are, as these are likely to be optimistic and difficult to achieve. It is important not to assume that increased time communicating through social media is necessarily internet addiction, as this may be meeting their need for social interaction. What is important is that this does not unduly restrict supported opportunities for offline social contact, which may need to be carefully managed. Although it may be difficult to judge how much internet use is too much, as long as social media use is not restricting young people from being involved in other aspects of day-to-day life or decreasing levels of well-being, it should not be discouraged. In cases where there is clear scope for a positive impact with regard to developing online friendships that can be continued offline, social media use should be encouraged.

5.5 Relating this research to personal, professional practice

This research has been a journey of personal reflection on my day-to-day EP practice, particularly with specific cases of young people who appear to have or show signs of ASC, who refuse to go to school and/or leave their rooms and spend the majority of their time using their computer. I have been able to communicate to parents that their use of social media may be the only social communication with peers they are getting in their lives and although it may seem that social media is maintaining the addiction, removing all use of the internet could lead to them becoming even more isolated as they would no longer have opportunities for communication beyond their family. In general, this research suggests that a balanced, moderate approach to social media use is required.

In other pieces of case work, I have encouraged schools and outreach workers to be creative with their communication with young people who are struggling with social communication. For example, I worked with a young boy who was struggling to engage with any professionals, but was a competent user of social media and online communication. Following my suggestions, he was able to engage with an outreach worker via email, which led to the development of their relationship and his increasing compliance in relation to the completion of school work. Over time, he received work set by the class teacher on a regular basis and returned completed tasks. By the end of the academic year, he was able to attend school and complete some GCSEs. Although the young person was not able to attend school full-time, this intervention involving the creative use of social communication by members of staff, enabled a young person to achieve academically in a way that did not appear possible prior to my involvement.

Other pieces of casework where I have been able to reflect on my findings, often involve young people who receive a diagnosis of ASC in early adolescence and have struggled to understand what it means. Where I have been able to encourage them to use online fora such as Wrong Planet and National Autistic Society, they have reported to key members of staff at school that they have begun to see their difference as something that should be celebrated, considering that they are more able to meet people online who often share the same interests as them. Similarly, it was reported to me that these young people were able to share strategies for use in the offline world with other young people with ASC. This is another important function of social media use in young people with ASC that EPs can publicise and disseminate.

One key point of reflection with regard to my personal, professional EP practice is whether the participants in this study are representative of the individuals that are

referred for EP involvement. Most young people with ASC that I have been involved with have had very high levels of need and their social functioning has been highly compromised, leading to significant distress. Many of the participants in this study had developed good coping strategies, some of which involved use of social media. It may be that in future research, the population in question should be young people who are particularly vulnerable and unable to engage with the offline world.

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Appendix

Appendix 1. Information sheet

Project Title:

What are young people with Autism Spectrum Condition's (aged 14-19) views on their use of social media?

The information below is to help you understand the project, and what your participation means. There is an email address below if you require further information.

What is the aim of the research?

Phase 1: To explore young people with ASCs digital identity and its relationship to; ability to form meaningful relationships, psychological well-being and life outcomes.

Phase 2: To explore in-depth the views of specific young people with ASC (aged 14-19) with varied digital identity in relation to their digital identity; and how it influences their relationship formation, psychological well-being and life outcomes.

What is the location and duration of the research?

The project will run from March 2017 until June 2018.

What will the project involve?

For phase 1, young people (aged 14-19) with a diagnosis of ASC who are internet users, will be asked to complete a short questionnaire which looks at; digital identity, friendships, well-being and life outcomes. The digital identity, friendships and well-being parts of the questionnaire have been taken from other studies and all been standardised. At the end of the questionnaire each participant will be asked if they are willing to take part in phase 2; if so they can enter their email address. For phase 2 there will then be an online forum-based discussion, where questions will be asked to ascertain more in-depth information about the four constructs outlined; digital identity, friendships, well-being and life outcomes.

What happens to the data collected?

The data will be analysed by Alec de Sausmarez for his doctoral thesis and a research report will be written. No data regarding individual participants will be published.

How is confidentiality maintained?

No confidential data will be asked for during both phases of the questionnaire. All data provided will be treated as confidential and anonymous. All email addresses will be kept confidential on a password protected laptop. The only people who will see the raw data will be Alec de Sausmarez, Brahm Norwich and Margie Tunbridge.

Will we be paid for taking part?

Unfortunately, there is no financial incentive for taking part in this study. However, the

research may lead to ideas to support and aid the understanding of young people with ASCs use of the internet.

What previous experience does the researcher have?

I have a wide range of experience working with young people with ASC. I have worked in a mainstream secondary school in a learning support unit, a school for individuals with special educational needs, a variety of live-in residential camps and most recently with my current role as a Trainee Educational Psychologist.

Ethics and safeguarding:

There has been thorough considerations to ensure this project is ethical. Approval has been received from the University of Exeter's ethics committee.

Where can I obtain further information if I need it?

Please email ad564@exeter.ac.uk.

Appendix 2. Online consent

Thank you for agreeing to be part of this study, this questionnaire should only take 10-15 minutes.

All data is anonymous, and nothing can be traced back to you.

This research is being done for a Doctoral Thesis in Educational, Child and Community Psychology at Exeter University, UK.

If you wish to ask any questions, please email Alec de Sausmarez (ad564@exeter.ac.uk). Alternatively, Alec de Sausmarez is being supervised by Brahm Norwich (B.Norwich@exeter.ac.uk) and Margie Tunbridge (M.A.Tunbridge@exeter.ac.uk).

There are two phases to this study. If you are happy to take part in the second phase, please fill in your email address at the end (otherwise leave it blank).

There are no right or wrong answers, please just be as accurate as you can.

Please tick the box below if you agree that:

- You have read the Information Sheet - see:
<https://docs.google.com/document/d/1DCDnccjxIdejubMmhB95yA55VKvyzTQByCeQC5LkmM8/edit?usp=sharing>.
- You have received enough information about the study.
- You understand the information given in the questionnaire will be used anonymously and only for this research project (which may also include publications).
- You are free to withdraw at any point (without reason and have your data destroyed), or not answer any question.
- IF you are under 14-17, have permission from your parent/guardian to complete this questionnaire (if you are 18 or 19 you can ignore this).

☐ **I** have read all necessary information and I agree to take part in this research.

Appendix 3. School consent

Dear Parent/Guardian,

Project Title; *What are young people with Autism Spectrum Conditions' (aged 14-19) views on their use of social media?*

I am writing to you regarding a research project taking place on the University of Exeter Educational, Child and Community Psychology course. We are looking for participants aged 14-19 who identify, or have a diagnosis of autism, who are social media users. Therefore, I am inviting your child to take part in phase 1 of this study; an online questionnaire. Should they wish, they are welcome to take part in phase 2 by supplying their email address at the end of the phase 1 questionnaire.

If you wish to ask any questions, please email Alec de Sausmarez (ad564@exeter.ac.uk). Alternatively, I am being supervised by Professor Brahm Norwich (B.Norwich@exeter.ac.uk) and Dr Margie Tunbridge (M.A.Tunbridge@exeter.ac.uk) who are both tutors at the University of Exeter.

The information below is to help you understand the project, and what your child's participation will mean. There is an email address below if you require further information.

What is the aim of the research?

Phase 1: To explore young people with Autism Spectrum Disorder's digital identity and its relationship to; ability to form meaningful relationships, psychological well-being and life outcomes.

Phase 2: To explore in-depth the views of specific young people with ASD (aged 14-19) with varied digital identity in relation to their digital identity; and how it influences their relationship formation, psychological well-being and life outcomes.

What is the location and duration of the research?

The project will run from March 2017 until June 2018.

What will the project involve?

For phase 1, young people (aged 14-19) with a diagnosis of (or identify as having) ASD who are internet users, will be asked to complete a short questionnaire which looks at; digital identity, friendships, well-being and life outcomes. The digital identity, friendships and well-being parts of the questionnaire have been taken from other studies that have all been standardised. At the end of the questionnaire each participant will be asked if they are willing to take part in phase 2; if so they can enter their email address. **For phase 2** there will then be an online forum-based discussion, where questions will be asked to ascertain more in-depth information about the four constructs outlined; digital identity, friendships, well-being and life outcomes.

What happens to the data collected?

The data will be analyzed by Alec de Sausmarez for his doctoral thesis and a research report will be written. No data regarding individual participants will be published.

How is confidentiality maintained?

No confidential data will be asked for during both phases of the questionnaire. All data provided will be treated as confidential and anonymous. All email addresses will be kept confidential on a password protected laptop. The only people who will see the raw data will be Alec de Sausmarez, Brahm Norwich and Margie Tunbridge. When the project finishes, all raw data will be destroyed.

What previous experience does the researcher have?

I have a wide range of experience working with young people with ASD. I used to work at a specialist provision, have worked in a mainstream secondary school in a learning support unit, a variety of live-in residential camps and most recently with my current role as a Trainee Educational Psychologist at the Royal Borough of Windsor and Maidenhead.

Ethics and safeguarding:

There has been thorough consideration given to ensure this project is ethical. Approval has been received from the University of Exeter's ethics committee.

If you have any further questions please do not hesitate to email myself (ad564@exeter.ac.uk), Professor Brahm Norwich (B.Norwich@exeter.ac.uk) and/or Dr Margie Tunbridge (M.A.Tunbridge@exeter.ac.uk).

Yours faithfully,



Alec de Sausmarez
Trainee Educational Psychologist

ad564@exeter.ac.uk

Please fill in the consent form below and return to *chosen setting*;

| | | |
|--|-----|----|
| You have read the Information Sheet (see above). | YES | NO |
| You feel you have received enough information about the study. | YES | NO |
| You understand the information given in the questionnaire will be used anonymously and only for this research project (which may also include publications). | YES | NO |
| You are free to withdraw at any point (without reason and have your data destroyed), or not answer any question. | YES | NO |

Parental consent:

I have read the enclosed information sheet and am happy for my son/daughter to take part.

Your name:

Date:

Signature:

This research is being done for a Doctoral Thesis in Educational, Child and Community Psychology at Exeter University, UK. If you wish to ask any questions, please email Alec de Sausmarez (ad564@exeter.ac.uk). Alternatively, Alec de Sausmarez is being supervised by Brahm Norwich (B.Norwich@exeter.ac.uk) and Margie Tunbridge (M.A.Tunbridge@exeter.ac.uk).

There are no right or wrong answers, please just be as accurate as you can.

Please tick the correct response (or otherwise write).

| Male | Female | Other |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

[illegible]

| Formal | Self-diagnosis |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |

[illegible]

| Rural | Village | Small town | Town | City |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

[illegible]

Roughly how long have you used digital media as a means of communication?

| Less than 1 year | 1-2 years | 3-4 years | 5-6 years | 7+ years |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Roughly how many hours a day do you spend on digital media (e.g. social media, Instagram, blogs)?

| Less than 30 minutes | 30 mins – 1 hour | 1-2 hours | 3-4 hours | 5+ hours |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Other (please write...)

Digital identity

Please tick the box to indicate your answer.

| | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
|---|-------------------|----------|------------|-------|----------------|
| When online, I would call myself autistic | | | | | |
| I feel that I am part of an online community with other people with autism | | | | | |
| When online, I am comfortable with other people who have autism | | | | | |
| Being involved online with other people who have autism is an important part of my life | | | | | |
| Being autistic is an important part of my online identity | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |
| <i>You enjoy.....</i> | | | | | |
| | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| Reading online articles by others who are autistic or talk about autism | | | | | |
| Posting on forums or engaging in online discussions with other people with autism | | | | | |
| Talking individually to other people with autism online | | | | | |
| Participating in activities that promote the rights of people with autism | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |

| <i>If you could have your way, how would you prefer the following situations in your life to be like...</i> | | | | | |
|---|--------------------------|-----------------|-------------------|--------------|-----------------------|
| | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| I would prefer my education to be at a school with only people with autism | | | | | |
| I would prefer my closest friend(s) to have autism | | | | | |
| I would prefer my family members to have autism | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |
| <i>How well do you know about....</i> | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| Teenagers with autism | | | | | |
| Names of well-known people who have autism | | | | | |
| Important events in the history of autism | | | | | |
| Organisations run by and for people with autism | | | | | |

| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|-------------------|----------|------------|-------|----------------|
| When online, I don't call myself autistic | | | | | |
| Meeting people online who are not autistic is an important part of my life | | | | | |
| Online, I hope to appear not to have autism | | | | | |
| When online I feel I am part of the same group as people who are not autistic | | | | | |
| When online I am comfortable with people who are not autistic | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |
| <i>You enjoy....</i> | | | | | |
| | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| Reading online articles that are written by people who are not autistic | | | | | |
| Posting on forums or engaging in online discussions with other people who are not autistic | | | | | |
| Talking individually to other people who are not autistic online | | | | | |
| Participating in activities with people who are not autistic | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |

| <i>If you could have your way, how would you prefer the following situations in your life to be like...</i> | | | | | |
|---|--------------------------|-----------------|-------------------|--------------|-----------------------|
| | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| I would prefer my education to be at a mainstream school | | | | | |
| I would prefer my closest friend(s) to not be autistic | | | | | |
| I would prefer my family members to not be autistic | | | | | |
| If you have any further comments on any of these answers, please enter here. | | | | | |
| <i>How well do you know about....</i> | Strongly disagree | Disagree | Neutral/NA | Agree | Strongly agree |
| Teenagers who are not autistic | | | | | |
| Names of well-known people | | | | | |
| Important events in world history | | | | | |
| Organisations run by and for people local to you | | | | | |

Friendships

For each of the following questions, tick the box next to the statement which most applies to you.

Question 1:

| | |
|---|--|
| I have one or two best friends. | |
| I have several friends who I would call best friends. | |
| I don't have anybody who I would call a best friend. | |

Question 2:

| | |
|---|--|
| The most important thing about a friendship is having somebody to confide in. | |
| I have several friends who I would call best friends. | |

Question 3:

| | |
|---|--|
| If I had to pick, I would rather have a friend who enjoys doing the same things as me than a friend who feels the same way about life as I do. | |
| If I had to pick, I would rather have a friend who feels the same way about life as I do, than a friend who enjoys doing the same things as me. | |

Question 4:

| | |
|---|--|
| I like to be close to people. | |
| I like to keep my distance from people. | |

Question 5:

| | |
|--|--|
| When I talk with friends on the phone, it is usually to make arrangements rather than to chat. | |
| When I talk with friends on the phone, it is usually to chat rather than to make arrangements. | |

Question 6:

| | |
|---|--|
| I tend to think of an activity I want to do and then find somebody to do it with. | |
| I tend to arrange to meet somebody and then think of something to do. | |

Question 7:

| | |
|---|--|
| I prefer meeting a friend for a specific activity, e.g., going to the cinema, playing golf. | |
| I prefer meeting a friend for a chat, e.g., at a pub, at a café. | |

Question 8:

| | |
|---|--|
| If I moved to a new area, I would put more effort into staying in touch with old friends than making new friends. | |
|---|--|

| | |
|---|--|
| If I moved to a new area, I would put more effort into making new friends than staying in touch with old friends. | |
|---|--|

Question 9:

| | |
|--|--|
| My friends value me more as someone who is a support to them than as someone to have fun with. | |
| My friends value me more as someone to have fun with than as someone who is a support to them. | |

Question 10:

| | |
|--|--|
| If a friend had a problem, I would be better at discussing their feelings about the problem than coming up with practical solutions. | |
| If a friend had a problem, I would be better at coming up with practical solutions than discussing their feelings about the problem. | |

Question 11:

| | |
|--|--|
| If a friend was having personal problems, I would wait for them to contact me as I wouldn't want to interfere. | |
| If a friend was having personal problems, I would contact them to discuss the problem. | |

Question 12:

| | |
|--|--|
| When I have a personal problem, I feel that it is better to work it out on my own. | |
| When I have a personal problem, I feel that it is better to share it with a friend. | |
| When I have a personal problem, I feel that it is better to try and forget about it. | |

Question 13:

| | |
|---|--|
| If I have to say something critical to a friend, I think it's best to broach the subject gently. | |
| If I have to say something critical to a friend, I think it's best to just come right out and say it. | |

Question 14: If I fell out with a good friend and I thought that I hadn't done anything wrong, I would....

| | |
|--|--|
| do whatever it takes to repair the relationship. | |
| be willing to make the first move, as long as they reciprocated. | |
| be willing to sort out the problem, if they made the first move. | |
| not feel able to be their close friend anymore. | |

Question 15: My ideal working space would be.....

| | |
|--|--|
| in an office on my own, without any visitors during the day. | |
| in an office on my own, with an occasional visitor during the day. | |
| in an office with one or two others. | |
| in an open plan office. | |

For the next set of questions, please tick the box to indicate your answer.

Question 16: How easy do you find discussing your feelings with your friends?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 17: How easy would you find it to discuss your feelings with a stranger?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 18: In terms of personality, how similar to your friends do you tend to be?

| Very similar | Quite similar | Not very similar | Very dissimilar |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 19: In terms of interests, how similar to your friends do you tend to be?

| Very similar | Quite similar | Not very similar | Very dissimilar |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 20: How important is it to you what your friends think of you?

| Of no importance | Of little importance | Fairly important | Very important | Of upmost importance |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 21: How important is it to you what strangers think of you?

| Of no importance | Of little importance | Fairly important | Very important | Of upmost importance |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 22: How easy do you find it to admit to your friends when you're wrong?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 23: How easy to do you find it to tell a friend about your weaknesses and failures?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 24: How easy do you find it to tell a friend about your achievements and successes?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 25: How interested are you in the everyday details of your close friends' lives (e.g., their relationships, family, what's currently going on in their lives)?

| Completely disinterested | Not very interested | Quite interested | Very interested |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 26: How interested are you in the everyday details of your casual friends' lives (e.g., their relationships, family, what's currently going on in their lives)?

| Completely disinterested | Not very interested | Quite interested | Very interested |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 27: When you are in a group, how important is it for you to know the "gossip," (e.g., at work, school, church, parent group etc.,) (e.g., who dislikes who, who's had a relationship with who, secrets)?

| Of no importance | Of little importance | Fairly important | Very important | Of utmost importance |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 28: Do you work harder at your career/school work than at maintaining your relationships with friends?

| Yes | No | Equal |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 29: How often do you make plans to meet with friends?

| | | | |
|----------------------------|--------------------------|----------------------------|--------------------------|
| Once or twice a year | <input type="checkbox"/> | Once every couple of weeks | <input type="checkbox"/> |
| Once every 2 or 3 months | <input type="checkbox"/> | Once or twice a week | <input type="checkbox"/> |
| Once a month | <input type="checkbox"/> | 3 or 4 times a week | <input type="checkbox"/> |
| More than any of the above | <input type="checkbox"/> | | |

Question 30: How would you prefer to keep in touch with friends? (Please put: 1 in the box next to your most preferred method, 2 in the box next to your second preference, 3 in the box next to your third preference)

| Face to face contact | Email/letters/social media | Telephone calls |
|--------------------------|----------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 31: How easy to do you find it to make new friends?

| Very easy | Quite easy | Not very easy | Quite difficult | Very difficult |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Question 32: What would be the minimum social contact you would need to get through a day?

| | | | | |
|-------------------------------|---|---|--------------------------|--|
| No contact—I don't get lonely | Just being near to people, even if I am not talking to them | A casual chat, e.g., with a shop assistant or hairdresser | A chat with a friend | Two or three chats with friends during the day |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| More of the above | | | <input type="checkbox"/> | |

Question 33: What would be the minimum social contact you would need to get through a week?

| | | | | |
|-------------------------------|---|---|--------------------------|--|
| No contact—I don't get lonely | Just being near to people, even if I am not talking to them | A casual chat, e.g., with a shop assistant or hairdresser | A chat with a friend | Two or three chats with friends during the day |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| More of the above | | | <input type="checkbox"/> | |

Question 34: When talking with friends, what proportion of your time do you spend talking about the following (Please put: 1 in the box next to your most preferred method, 2 in the box next to your second preference, 3 in the box next to your third preference):

| | | | |
|---|--------------------------|--|--------------------------|
| Politics/current affairs | <input type="checkbox"/> | Family & Friends | <input type="checkbox"/> |
| Hobbies and interests | <input type="checkbox"/> | The weather | <input type="checkbox"/> |
| Personal matters (e.g., feelings, life choices) | <input type="checkbox"/> | What you have been doing since the last time you spoke | <input type="checkbox"/> |
| Work | <input type="checkbox"/> | | |

Question 35: At social occasions, when you meet someone for the first time, how likely are you to talk about the following. (Please put: 1 in the box next to your most preferred method, 2 in the box next to your second preference, 3 in the box next to your third preference):

| | | | |
|---|--------------------------|--|--------------------------|
| Politics/current affairs | <input type="checkbox"/> | Family & Friends | <input type="checkbox"/> |
| Hobbies and interests | <input type="checkbox"/> | The weather | <input type="checkbox"/> |
| Personal matters (e.g., feelings, life choices) | <input type="checkbox"/> | What you have been doing since the last time you spoke | <input type="checkbox"/> |
| Work | <input type="checkbox"/> | | |

Well-being:

This form is about how you might have been feeling or acting recently.

For each question, please check how you have been feeling or acting in the past two weeks.

If a sentence was not true about you, check NOT TRUE.

If a sentence was only sometimes true, check SOMETIMES.

If a sentence was true about you most of the time, check TRUE.

Some of these questions may be difficult to answer, at any point you can leave these questions and move on to the next part of the questionnaire.

| Please tick your chosen statement. | Not true | Sometimes | True |
|---|----------|-----------|------|
| 1. I felt miserable or unhappy | | | |
| 2. I didn't enjoy anything at all. | | | |
| 3. I felt so tired I just sat around and did nothing. | | | |
| 4. I was very restless. | | | |
| 5. I felt I was no good anymore. | | | |
| 6. I cried a lot. | | | |
| 7. I found it hard to think properly or concentrate. | | | |
| 8. I hated myself. | | | |
| 9. I was a bad person. | | | |
| 10. I felt lonely. | | | |
| 11. I thought nobody really loved me. | | | |
| 12. I thought I could never be as good as other people. | | | |
| 13. I did everything wrong. | | | |

Life outcomes

Please rate each statement on how true it is for you.

Through online communication, I am more likely to find employment.

| Definitely false | Somewhat false | Neither true nor false | Somewhat true | Definitely true |
|--------------------------|--------------------------|---------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Because of online communication, I will be able to make more friends.

| Definitely false | Somewhat false | Neither true nor false | Somewhat true | Definitely true |
|--------------------------|--------------------------|---------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Because of online communication, I am less likely to meet a long term partner.

| Definitely false | Somewhat false | Neither true nor false | Somewhat true | Definitely true |
|--------------------------|--------------------------|---------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Because of online communication, I am less likely to achieve in school/college.

| Definitely false | Somewhat false | Neither true nor false | Somewhat true | Definitely true |
|--------------------------|--------------------------|---------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Any further comments you have, please add here.

Thank you for your participation. If you are happy to be contacted and be involved in the second part of this study, please enter your email address below.

Appendix 5. Coded Questionnaire surplus responses

Choosing/Disclosing the ASC Identity

bit sometimes I feel the need to tell people.

Difficulties with ASC Identity

It is important to understand that i wouldn't wish autism on anyone. It is also important to associate with non-autistic people to pick up on there Behavior and emotional reactions under certain situations so that we can gain a better understanding of normal behavior

Choosing not to identify as ASC online

Never mentioned to anyone about being autistic and I just read the posts on /r/Aspergers.

I haven't told many of my online friends

I like to separate the part of me that identifies as autistic and save that for autism communities rather than it always being a part of me whilst online. Although I do like to talk about autism sometimes, I prefer focusing on other things the majority of the time.

I personally don't go around saying im autistic to everyone in ear shot its more me trying to help people blend in with society so they don't become a victim of abuse or bullying because they are autistic

I feel comfortable online with people who aren't autistic, as we normally have other things in common or have had similar experiences to talk about instead

I don't tell people unless they ask

In some ways I prefer interacting with neurotypical people so that I can just discuss the things that I go online for, which is usually my special interest (TV and film).

I don't always want to discuss autism as sometimes it frustrates or exhausts me that I am different, and I also just don't see autism as my entire identity.

Sometimes there is no need to tell people I'm autistic

Advantages of being online

Being online makes the social aspect easier.

Learning about friendships

It is also important to associate with non-autistic people to pick up on there Behavior and emotional reactions under certain situations so that we can gain a better understanding of normal behavior

Autism isn't really spoken about much, but I get the majority of my information from autism communities or from the National Autistic Society who I follow on Facebook and Twitter.

Meeting new people

It's easier to connect with others who have autism online than in person

I like to see other people's views and experiences as lots of people experience autism differently

Close family already are all autistic. Would be nice to have someone outside of family who understands me though.

I have very few friends and the ones I do have pretty much all have autism or adhd or both

Being surrounded by people who don't have autism, has pushed me to improve my communication skills

I get on with neurotypical people very well when they are patient and understanding, however my autistic friends are separate from my neurotypical friends as I have met them online in Facebook communities as opposed to not knowing/being friends with almost any autistic people in person. It would also be nice to not be the only autistic person in my family so that I don't feel so alone sometimes.

Need neurotypical people around to assimilate and learn to fit in better

I think that socializing with people who don't have autism is just as important as with people who have it is. So I don't agree with an autism only school.

Stress in friendships

the last question i dont like being with other people its so unconformable being around other with the same thing because you don not know how they will act or even if they get upset with something you both disagree with.

Social support

When I do engage myself in autistic communities, I do like to discuss issues that I and others have, as well as looking up things that I might

Appendix 6. Coded forum data

Digital Identity: Choosing/disclosing the ASC identity

the online world is worth taking advantage of if it works for you. Why should I force myself to socialise at neurotypical standards if that creates high

Digital Identity: Choosing not to use ASC identity online

I feel like social awkwardness isn't so obvious online, if that makes sense?

Friendships: Advantages online

It has also made me happier by improving my confidence, as when I am online I tend to be more outgoing, as I find it a lot easier to communicate through social media instead of face to face. I can start up conversations or join in conversations really easily which I wouldn't have the confidence to do in person.

I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it.

I think being able to express myself online has also helped in my happiness and I have felt better since doing it.

Although being online has really helped me with my social life

I think being able to have a place to express myself has really helped me and I would recommend it to other people definitely. Blogging and other social platforms can be a great place to start.

Online has been my main method of social interaction, and therefore my activity online has been vital for my social well-being and happiness. Even though I may have a lower threshold of minimum social interaction than the average person, some social interaction is still highly necessary for any person.

I feel like I need far less input in social interactions than other people in order to be happy, but if I didn't have anything, I'd feel lonely very quickly. Being online means that I can talk to people when I have the energy to, and they won't necessarily mind if I need to step away for an hour or a day or so, whereas a person in real life may look at me weirdly if I were to walk away in the middle of a conversation

I think being online, for the most part, has increased my ability to form meaningful relationships with people. I find it difficult to trust people in real life because I see friendship groups break down incredibly easily and then their dirty laundry is aired out for everyone to see, but there isn't that same thing online. It's rare that someone will dish out everything they can online if you fall out, and even if they do, it's not like others will fall out with you, because there's less chance of them finding the information.

It's a great way of catching up informally, especially as people usually talk about what they're doing online so you have a topic of interest to talk about when you do chat.

Yeah, I can definitely agree with what you've said about having that place to escape to where you had people who didn't know what you had or didn't have and were happy to be your friends because they genuinely liked you

I also think there's a lot that can be learned from the online world. I don't know whether this is a trait a lot of autistic people share, but with my logical tendencies, I also want to know how things work and why which puts me in a great place when it comes to learning things online. I'm not necessarily the best at technology, but my determination to know how things work means I've learned skills like basic coding and how to do animation and stuff simply by researching because I'm determined to do something I couldn't before.

Friendships: Lower stress in online communication

I can start up conversations or join in conversations really easily which I wouldn't have the confidence to do in person

Being online means that I can talk to people when I have the energy to, and they won't necessarily mind if I need to step away for an hour or a day or so, whereas a person in real life may look at me weirdly if I were to walk away in the middle of a conversation.

I feel like I don't have to be ashamed of my social awkwardness and I can embrace it. in real life, people give me funny looks.

I can take time to give across the point I want to give and edit it if something I write doesn't make much sense until I'm happy with it. There aren't so many rules--you can't make eye contact, or stand incorrectly, or do many things wrong online, but in real life, it's a completely different minefield and everyone else seems to have been given the map showing how to avoid them, meaning you're the one who constantly messes up and lands yourself in trouble!

Being active online has made it a lot easier to form relationships, as when you are talking to someone online or on social media you don't have to worry about things like making eye contact or thinking of an answer immediately, which can be really difficult. I can have conversations which I would normally avoid (because face to face talking is really daunting to me) online which takes away a lot of stress.

online which takes away a lot of stress. This makes it easier to form relationships with people as I can just concentrate on what they are saying, get to know them more and have a really laid-back conversation, without getting stressed by talking to them

I don't know, I felt like I could have more genuine friendships online, without the added pressure of social cues and rules and stuff.

I also feel like you can be more genuine online. In rea life, it's so hard to be yourself without getting judged a lot. It's kinda stupid how much people judge you in the real world. Just because you're not a sheep, it doesn't mean that you're worthy of being looked down upon.

When I have gone to interviews before, I have completely panicked and not known what to say. With my last employer, they allowed me to take an online interview instead in which I passed with flying colors.

Personally, I find being able to write my thoughts out and then editing them gives me a much better opportunity to properly express myself, letting me take the time I need with replies, instead of giving a rushed response that constantly requires fixing and clarification.

When making contact with businesses or government institutions I much prefer email over telephone, as the pressure of not coming across as an idiot often hampers my ability to get the information I need.

lot of employers are getting on board with the online world now, with advertisements for job positions and application forms now taking place on the internet, where you can send your CV and information over to an individual in a company without having to speak to them verbally. This allows those of us who struggle with spontaneous speech, or speech in general, to have a chance at job opportunities that may not have been an option years ago.

My nervousness around communication, and social anxiety disorder in general, make it impossible for me to call people, so I can say with 100% confidence that if it wasn't for online communication then I wouldn't have anywhere near as many opportunities presented to me.

I think perhaps the only downside is that, because I find verbal speech far more difficult than online communication methods, I have a tendency to ramble on far more than needed to.

I find myself stumbling over my words when I'm expected to say something outside of what I've scripted, and it takes longer and more misunderstandings before the conversation is over.

Yeah, I can't call people either. I struggle a lot with stuff like that. I think the increasing presence of online opportunities is really useful for us, as we can find stuff on the internet that fits in with us. As someone who gets anxiety over any social situation, this is really cool.

Friendships: Learning about relationships

learnt to trust people, and how to build healthy relationships with people, through the experiences I've gained online.

I wouldn't know half the coping mechanisms I do if it wasn't for recommendations from people online, especially regarding problems I have that I wouldn't talk about in real life.

Friendships: Meeting new people

Being online has made me a lot happier, as it has given me a platform to meet and connect with people who I wouldn't have had the opportunity to meet otherwise.

I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it. I am not a social person so it really helps that I can be sociable online. I think being able to express myself online has also helped in my happiness and I have felt better since doing it.

Being online, has really helped me make new friends and find environments that I can thrive in and form lasting friendships with.

I didn't receive my diagnosis until I was seventeen, so seeing other people online being positive about their condition definitely helped me to accept that it wasn't a bad thing or something I needed to be ashamed of. It also made me feel like I belonged as part of a community, something all humans arguably need, whereas I had felt like I stood out like a sore thumb my whole life. I finally had a whole heap of people who could relate to my experiences, and I didn't even need to get out of bed. It was like discovering a whole other world full of acceptance, and I've loved it since.

Through my blogging, I have also seen different perspectives in the world, and I began to understand the world of people who aren't like me. One of my best friends, not autistic, was formed through

it wasn't until I got really involved in the online community that I realised just how different people can be. It's definitely helped me emphasise with larger, more diverse groups of people. an online friendship

The use of online communications has really helped me thrive and make new friends

Friendships: more friends online

Being active online has made it a lot easier to form relationships

I have formed a lot of friendships online. I would not have many friends at all if it hadn't been for the online communities I have joined.

Although the few friends I have are friends I have met elsewhere, the Internet has been the main way to keep in contact with my friends

Without the Internet I doubt any of my friends would still be engaging with me in any way at all, and in fact, there are friends I have lost contact with due to their minimal presence online

I have far more online friendships, though, some of which have lasted years.

I have another online friendship which has lasted in excess of four years now, and we're still going strong.

Being active online was the best choice for me when trying to form relationships with Asperger's.

met my boyfriend three and a half years ago on Tumblr and my current closest friends went to my secondary school but we didn't really know each other that well but then started talking on Facebook a year ago and now hang out all the time.

Friendships: Relationship difficulties

although I have formed many online communications and friendships, I have lost almost all my offline relationships and I don't really leave the house anymore.

I have made so many online friends, i can't meet up with any of them and often they are from different time zones so my sleeping patterns get messed up trying to chat to them.

I have made a point of this year to try and make some offline friends and although I have not made very many, I frequently meet up with the few friends I have made.

time zones can definitely be a problem! I've experienced difficulty with this in the past

Well-Being: Higher well-being

Being online has made me a lot happier, as it has given me a platform to meet and connect with people who I wouldn't have had the opportunity to meet otherwise. It has also made me happier by improving my confidence, as when I am online I tend to be more outgoing, as I find it a lot easier to communicate through social media instead of face to face.

I have been happier since being online, it has provided me with a form of social communication which I could not have gotten if I didn't have it.

I think being able to express myself online has also helped in my happiness and I have felt better since doing it.

Online has been my main method of social interaction, and therefore my activity online has been vital for my social well-being and happiness

Being active online has had such a crucially positive effect on my well-being over the years.

It also made me feel like I belonged as part of a community, something all humans arguably need, whereas I had felt like I stood out like a sore thumb my whole life. I finally had a whole heap of people who could relate to my experiences, and I didn't even need to get out of bed. It was like discovering a whole other world full of acceptance, and I've loved it since.

the online world is worth taking advantage of if it works for you. Why should I force myself to socialise at neurotypical standards if that creates high anxiety?

I love being online, it makes me very happy! I have been able to meet others just like me for the first time in my life which makes me less alone and depressed. Its overall just improved my moos and interactions with others my age.

Well-Being: Lower well-being

I got addicted and spent my whole life inside. As I result I was unhappy and misses out whole periods of my life.

I was cyber bullied as a child and as a result I lost all my confidence. For a large period of my life, I didn't talk to anyone and lost contact with all my friends. I sought help from a councilor who I still see and she helped me so much with my self confidence and I have grown as a person.

Well-Being: Difficulties with online relationships

in the long run I have frequently linked being online to my times of unhappiness. I got addicted and spent my whole life inside. As I result I was unhappy and misses out whole periods of my life. Recently, I got a puppy, and the training and care she needs has drawn me away from the internet and as a result, I have been happier and have even found a partner.

I was cyber bullied as a child and as a result I lost all my confidence. For a large period of my life, I didn't talk to anyone and lost contact with all my friends. I sought help from a councilor who I still see and she helped me so much with my self confidence and I have grown as a person.

I have made so many online friends, i can't meet up with any of them and often they are from different time zones so my sleeping patterns get messed up trying to chat to them

time zones can definitely be a problem! I've experienced difficulty with this in the past, though I have sleeping problems which made it a little easier as I don't sleep much anyway.

i have also suffered with sleeping problems in the past and I found that asmr really helped me

Well-Being: Social support

Being online has made me a lot happier, as it has given me a platform to meet and connect with people who I wouldn't have had the opportunity to meet otherwise. It has also made me happier by improving my confidence, as when I am online I tend to be more outgoing, as I find it a lot easier to communicate through social media instead of face to face. I can start up conversations or join in conversations really easily which I wouldn't have the confidence to do in person.

It also made me feel like I belonged as part of a community, something all humans arguably need, whereas I had felt like I stood out like a sore thumb my whole life. I finally had a whole heap of people who could relate to my experiences, and I didn't even need to get out of bed. It was like discovering a whole other world full of acceptance, and I've loved it since.

I have been able to meet others just like me for the first time in my life which makes me less alone and depressed.

I felt like there were people online who understood my quirky and unusual ways and felt the same. it was nice to feel like I fitted in somewhere

I definitely have quirks which online friends accepted far quicker than real life friends, though. I was known as the weird one of our online friendship group, the one who had very little common sense, but I wasn't treated differently for it like I was in real life. Online communities really taught me that even though kids are cruel and don't accept you now, you will find a group of people who will cherish your presence one day, quirks and all. I definitely feel like I fit in more with people online, even if we didn't necessarily share entirely the same interests, than people who I may know very well in real life.

Although I no longer talk to them regularly, a group of girls I met on a writing website at the age of twelve got me through of some of my most difficult years as a young teenager. We were there to support each other, and there wasn't the same pressure when it came to keeping certain things to yourself.

we built up trust in the same way you would in a real life friendship. We share snippets of each other's lives with each other, like what's going on in college and stuff, as well as about deep stuff and things that are troubling us as we're both great at giving advice.

I wouldn't know half the coping mechanisms I do if it wasn't for recommendations from people online, especially regarding problems I have that I wouldn't talk about in real life

People you meet online are also easier to open up to and I feel like they can be a massive support when you're at your lowest; I know for a fact I wouldn't be here if it wasn't for the times my friends went out of their way to talk me out of things, as I hope I did with them.

Life Outcomes: Confidence

I think online communication helps me with future employment as otherwise I would not have any prospects, because I am not confident enough to go places and ask for jobs. sometimes, opportunities come my way online.

I agree with you, I also have issues going places and talking to people so being able to use online communications can really help with applying to jobs and getting my CV out there.

When I have gone to interviews before, I have completely panicked and not known what to say.

Life Outcomes: Employment opportunities

With my last employer, they allowed me to take a online interview instead in which I passed with flying colors.

When making contact with businesses or government institutions I much prefer email over telephone, as the pressure of not coming across as an idiot often hampers my ability to get the information I need.

My nervousness around communication, and social anxiety disorder in general, make it impossible for me to call people, so I can say with 100% confidence that if it wasn't for online communication then I wouldn't have anywhere near as many opportunities presented to me.

i think it will help future employment for me, as id prefer to work behind a screen or with technology than with people face-to-face. i am also much more productive and helpful with online work than paper-work so i would be able to do my job more efficiently.
